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**Authority, Futility, and Clinical Treatment:
The Challenge to Authority**

By

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**Dissertation Presented to the School of Graduate Studies in Partial Fulfilment of the
Requirements for the Degree of Doctor in Philosophy**

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Dedicated To my Perfect Wife, Kembubi Christie.

And in Loving Memory of My Late Grandfather, Gerry Christie.

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Abstract

The doctrine of informed consent established a distinctive role for both the doctor and the patient, in the doctor-patient relationship. This doctrine, represented by the compound word “informed consent,” placed a duty on the physician to “inform” and gave a specific task to the patient “consent.” The physician was required to inform the patient to the extent that a reasonable person in that situation would want to be informed. Then the patient had the prerogative of whether to consent or refuse to consent.

However, during the late 1980's and early 1990's different clinical situations arose which could not be accommodated by simply giving patients the right to consent or refuse to consent. Situations developed in which health care professionals wanted to refuse to provide treatment on the grounds that further treatment is medically futile and patients' (and/or their families) wanted to insist on treatment claiming that it was not futile and that it served a genuine purpose. Essentially, the informed consent doctrine provided patients with the “negative right” to refuse treatment. The idea of medical futility revealed the limitations of informed consent by demonstrating that some patients also wanted a “positive right” to demand treatment.

After analysing this new phenomenon it appears that it is the most recent manifestation of the age-old debate between professional paternalism and patient autonomy. As a result, this thesis analyses the futility debate and then takes a step back in order to evaluate it from the more general perspective of establishing the legitimate domains of both patient and professional authority.

Standard approaches to the futility debate generally argue for unilateral decision-

making authority for either the patient or professional, concerning futility issues. However, the problem with this approach is that it renders the doctor-patient relationship as a zero-sum game; in other words, if one side wins the other side loses. Alternatively, the focus of this thesis is to propose a model of professional and patient authority which allows each party substantial decision-making authority but is also mutually supportive. Therefore, this new approach to the futility debate, and indeed the doctor-patient relationship in general, is undertaken with the intention of preventing these types of disputes from arising, rather than attempting to resolve the conflict once it is fully developed.

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Introduction

The principle of respect for individual autonomy has been a major theme in the recent history of philosophy. To paraphrase Albert Camus, the question of the capacity of a person to exercise control over his or her own life is an important philosophical question. In the context of real life situations, conflicts can arise about the determination of the best course of action, spurred by divergent conceptions of autonomy. This thesis is not about autonomy, per se, but about situations where not only conceptions of autonomy may clash, but where the dispute arises about exactly how the expression of the autonomy of one person can coexist with the expression of the autonomy of another. Since authority is one of the central concepts that will be considered in this thesis it is important to look at the concept of autonomy. The idea of authority carries not only an expression of autonomy of judgment and action, but also of the legitimacy for action. In the context of medicine, knowledge and experience are among the chief factors that contribute to the legitimacy of the physician's authority, and therefore, to his or her autonomy. Keeping in that tradition, this thesis analyses recent developments pertaining to the way individuals conceive of this principle. Philosophy in general and ethics in particular cannot but be interested in this and must bring as much as possible to the new debate in an effort to sort out and solve this issue.

Philosophical Foundations of the Principle of Respect for Autonomy

Individual autonomy has been a topic of interest for philosophers, at least since the 18th century. For instance, Immanuel Kant and John Stuart Mill have contributed substantially to the contemporary understanding of this principle. Their conceptions have been influential on the development of law and jurisprudence as well as on the recent evolution of medical ethics. In both fields, the principle of respect for autonomy has influenced the development of the doctrine of informed consent, which is currently a central piece in the practice of medicine and medical law.

Kantian deontology and Mill's version of utilitarianism are both greatly concerned with autonomy. However, their respective conceptions of what autonomy means are quite different. Autonomy in a Kantian sense has to do with the power of reason to self-legislate and, ultimately, to submit oneself to this self-given law. One has to choose actions according to the right motives. These motives cannot be solely the result of individual inclinations, but must be universally acceptable to all rational beings.

We have also shown above how neither fear nor inclination, but solely reverence for the law, is the motive which can give an action moral worth. Our own will, provided it were to act only under the condition of being able to make universal law by means of its maxims---this ideal will which can be ours is the proper object of reverence; and the dignity of man consists precisely in its capacity to make universal law, although only on condition of being himself also subject to the law he makes.

Autonomy of the will is the property the will has of being a law to itself (independently of every property belonging to the objects of volition). Hence the principle of autonomy is 'Never to choose except in such a way that in the

same volition the maxims of your choice are also present as universal law.’¹

Therefore, according to Kant, the autonomous person will place himself or herself under the governance of reason for the choice of actions. Under Kant’s theory, individual autonomy is realizable by all rational creatures. This mere possibility is the ground of our obligation to respect all human beings. However autonomy is not achieved by all since some people let themselves be governed by their inclinations, heteronomous motives, when the time comes to choose a course of action.

Mill’s conception of autonomy differs and was developed in a quite different context.

Clearly, an autonomous agent will possess all the defining features of an autarchic agent: but, in addition to exercising capacities for rational reflection and strength of will in the objective choice---conditions which are not distorted by the presence of force or coercion, an autonomous agent must also have distanced himself in some measure from the conventions of his social environment and from the influence of the persons surrounding him. His actions express principles and policies which he has himself ratified by a process of critical reflection.²

Mill’s famous ‘bridge example’ provides some more information which helps us to understand further his conception of autonomy.

If either a public officer or anyone else saw a person attempting to cross a bridge which had been ascertained to be unsafe, and there were no time to warn him of his danger, they might seize him and turn him back, without any real infringement of his liberty; for liberty consists in doing what one desires, and he does not desire to fall into the river. Nevertheless, when there is not a certainty, but only a danger of mischief, **no one but the person himself can judge of the sufficiency of the motive which may prompt him to incur**

¹Kant, I., *Groundwork of the Metaphysic of Morals, Translated and analysed by H.J. Paton* (New York and Evanston: Harper & Row Publishers, 1961), pp. 106-107.

²Gray, J., “Mill’s Conception of Happiness and the Theory of Individuality,” in J. Gray and G.W. Smith (editors), *J.S. Mill on Liberty in Focus*, (London: Routledge, 1991), pp. 190-211.

the risk; in this case, therefore (unless he is a child, or delirious, or in some state of excitement or absorption incompatible with the full use of the reflecting faculty), he ought, I conceive, to be only warned of the danger; not forcibly prevented from exposing himself to it.³(Emphasis added)

In Mill's account of autonomy, judgment is paramount. If one is at liberty to cross an unsafe bridge, to use the example at hand, it is because one is the best judge of his or her own interests and one can be trusted for judging self-regarding matters. Autonomy is autonomy of judgment. Mill would put a limit to otherwise autonomous action when lack of information would impair judgment and cause one to act contrary to his or her real interests.⁴ However, any hindrance on the course of action indicated or initiated by someone requires a solid presumption that the person is about to make a mistake that she or he would refrain from doing if fully informed.

Kant is particularly relevant to this thesis because a recurring theme is that the individual patient has certain rights (i.e., to be treated as an end and not merely as a means). Mill on the other hand is very useful because he shows that in order for an individual to exercise any meaningful rights he or she must be sufficiently informed (i.e., the bridge example). Both of these themes are central to the shared decision-making model of the doctor-patient relationship that is developed in this thesis. The Kantian aspect is closely related to the rights of the individual patient, while Mill's ethics reflects the professional's duty to help the patient exercise his or her rights competently.

³Gray, J., "Mill's Conception of Happiness and the Theory of Individuality," in J. Gray and G.W. Smith (editors), *J.S. Mill on Liberty in Focus*, (London: Routledge, 1991) pp. 190-211.

⁴See for example Feinberg, J., *Harm to Self, The Moral Limits of Criminal Law, Volume 3* (New York: Oxford University Press, 1986), pp. 124-127.

Practical Concerns With the Principle of Respect for Autonomy

Although Deontology and Utilitarianism agree on the importance of individual autonomy, they disagree on their general approaches to ethics. Nevertheless, using these authors as examples helps to demonstrate that there has been a theoretical and practical concern with individual rights in the recent history of philosophy. In fact, this is still a major issue in both traditional ethics and the applied ethics fields today. Philosophers, in general, have been very concerned with establishing the theoretical foundations of ethics, and as a result until recently, have not been accustomed to addressing tangible contemporary issues.

Stephen Toulmin says:

[...] British and American moral philosophers treated ethics as a field for general theoretical inquiries and paid little attention to issues of application or particular types of cases.⁵

Regardless, this practical turn is being forced upon those concerned with ethics. For instance, consider the explicit concern with autonomy in Canadian Supreme Court Justice Wilson's decision concerning the *R v Morgentaler* abortion case:

Section 251 of the *Criminal Code*, which limits the pregnant woman's access to abortion, violates her right to life, liberty and security of the person within the meaning of s. 7 of the *Charter* in a way which does not accord with the principles of fundamental justice. [...] The right to "liberty" contained in s. 7 guarantees to every individual a degree of personal autonomy over important decisions intimately affecting his or her private life. Liberty in a free and democratic society does not require the

⁵Toulmin, S., "How Medicine Saved the Life of Ethics," *Perspectives in Biology and Medicine*, Volume 25, Number 4, (1973), pp 736-750.

state to approve such decisions but it does require the state to respect them.⁶

This statement helps to reveal the importance of a critical analysis of the concept of autonomy at both a theoretical and a practical level. This principle (autonomy) as discussed by Kant and Mill is not only a consideration in abortion or informed consent but also in politically charged debates like euthanasia and physician assisted suicide. In addition to Justice Wilson's discussion of the importance of respecting the principle of autonomy, consider a recent document which expanded on Kant and Mill's attempts at critical analysis and practical applications.

This item was a brief that was filed as an *amicus curiae* to the U.S. Supreme Court, and was authored by a distinguished group of philosophers: Ronald Dworkin, Thomas Nagel, Robert Nozick, John Rawls, Thomas Scanlon, and Judith Jarvis Thomson.⁷ This document is known as the "Philosophers' Brief" and it attempts to address the exceedingly important notion of physician assisted suicide and its constitutional implications. The captivating aspect of this brief is the explicit appeal to Kant and Mill's concern with the scope and limits of individual autonomy.

The "Philosophers' Brief" addresses the issue in two ways: the first is from a Kantian perspective:

First, it ["The Philosophers' Brief"] defines a very general moral and constitutional principle — that every competent person has the right to make momentous personal decisions which invoke fundamental religious or

⁶*R. v. Morgentaler*, [1988] 1S.C.R. 30.

⁷Dworkin, R., Nagel, T., Nozick, R., Rawls, J., Scanlon, T., and Thomson, J., "Assisted Suicide: The Philosophers' Brief," *The New York Review of Books*, Volume XLIV, Number 5, (1997), pp. 41-47.

philosophical convictions about life's value for himself.⁸

This implies the essence of the Kantian discussion that was mentioned above. In fact, in one formulation of his categorical imperative Kant says:

Act so that you treat humanity, whether in your own person or in that of another, always as an end and never as a means only.⁹

The "Philosophers' Brief" has taken this type of Kantian principle and applied it to real-life situations concerning physician assisted suicide. The "Philosophers' Brief" is subtly different from Kant's formulation but is similar concerning how other people must be treated.

In addition, the next point resembles the bridge example from Mill, just as closely:

Second, it ["The Philosophers' Brief"] recognizes that people may make such momentous decisions impulsively or out of emotional depression, when their act does not reflect their enduring convictions: and it therefore allows that in some circumstances a state has the constitutional power to override that right in order to protect citizens from mistaken but irrevocable acts of self-destruction. States may be allowed to prevent assisted suicide by people who — it is plausible to think — would later be grateful if they were prevented from dying.¹⁰

This is the same type of reasoning as Mill's Bridge Example, where he suggests that it is occasionally justified to interfere with an individual's right to self-determination. If it is clear that the individual is making a poor decision that is inconsistent with his or her goals,

⁸Dworkin, R., Nagel, T., Nozick, R., Rawls, J., Scanlon, T., and Thomson, J., "Assisted Suicide: The Philosophers' Brief," *The New York Review of Books*, Volume XLIV, Number 5, (1997), pp. 41-47.

⁹Kant, I., *Foundations of the Metaphysics of Morals*, 2ed: Translated by Lewis White Beck (New York: Library of Liberal Arts, 1990), p. 18.

¹⁰Dworkin, R., Nagel, T., Nozick, R., Rawls, J., Scanlon, T., and Thomson, J., "Assisted Suicide: The Philosophers' Brief," *The New York Review of Books*, Volume XLIV, Number 5, (1997), pp 41-47.

like the person who is ignorant of the fact that the bridge is going to collapse, the state is justified, to a limited extent, in intervening to make sure that the person is aware and really intends to do this, i.e., cross the bridge or make arrangements to terminate his or her own life with the assistance of a physician.

New Developments in Autonomy that have led to the “Medical Futility” Debate

Current discussions about abortion, physician assisted suicide, and euthanasia, etc., all place a heavy emphasis on the idea of respect for the principle of individual autonomy. As we have seen from Kant, Mill, and the “Philosophers’ Brief,” modern philosophical theory has also emphasized this concern. Thus, my analysis of this concept is situated within a rich philosophical tradition which has profound practical significance. These philosophical concerns are particularly relevant in the clinical setting, where respect for the principle of autonomy is most thoroughly discussed in terms of the informed consent doctrine. Therefore, I have used the first chapter of this thesis to explain the historical development and current context of informed consent and patient autonomy in this setting.

In health care, this principle has usually been considered as a “negative right.” As we have seen, for Kant, autonomy entails the right to be respected as a rational being and for Mill it is a right not to be unduly interfered with (the Bridge Example). However, around the late 1980's and early 1990's, a new dilemma has evolved concerning the end of life treatment of clinical patients, centring on the idea of medical futility. Medical Futility has raised the further issue, not of patients’ exercising their right to be respected or not interfered with but rather, of patients’ insisting on a specific course of treatment that the health care professionals

believe is futile.

In the clinical context, the proper role of patient autonomy is being obscured. It is no longer limited to interpretations that would be consistent with Kant and Mill or how the Supreme Court of Canada or the *Philosopher's Brief* interprets it. Instead, it is being asserted as an entitlement right, i.e., a right to demand treatment that is considered futile. Controversy arises, however, because within the clinical treatment context the term "futile" has a very different meaning from colloquial usage.

Standard usage of the word "futile" implies an objective meaning like: ineffective, useless, will not work, etc.; however, in the clinical setting this term has been divided into two different categories. The first refers to those treatments that have only a remote possibility of achieving the desired result. These have come to be called "quantitatively futile." Secondly, treatment is futile in a "qualitative" sense, if it will achieve the desired physiological effect, but the patient's quality of life is so compromised that further treatment should not be attempted (e.g., a respirator can support the breathing of a persistently vegetative patient but the patient cannot appreciate this benefit and will never recover).

When there is agreement that a particular intervention will not or cannot achieve a particular goal, the word "futile" serves a reasonable language function in reflecting a type of consensus. However, if there is disagreement the futility label itself adds very little to the debate. Controversy arises around this issue on many different levels, of which the following are only two: (1) It is not clear who should have the decision-making authority to impose a futility label, when there is disagreement. There is a substantial debate concerning futility which focuses on either patient or professional unilateral decision-making, concerning futility

and it is argued, on the other side, that since determining the worth of pursuing a remote possibility of success or of determining the quality of a patient's life, relies on value judgments the patient's values should determine these issues. However, on the other side, some advocates for professional unilateral decision-making suggest that it is not appropriate for patients to make these decisions because professionals simply should not be obligated to provide futile treatments to patients---that doing so violates their professional integrity. (2) There is also substantial opposition to specific thresholds for futility, and many commentators suggest abandoning the term altogether. If the term is accepted then there is a fear that it is properly within the exclusive domain of professional authority to decide. Likewise, some commentators suggest that professionals should not use this term because it is too pejorative to patients. Nevertheless, the issue of medical futility has generated an impressive debate which frames the issue as a power-struggle between patients and health care professionals. The power struggle is about who has the ultimate decision-making authority in these complicated circumstances. The second chapter of this thesis presents the issue of futility and the different arguments that constitute this power struggle.

I want to suggest that in these situations, there is a clash between, what I will call, the authority of the physician and the authority of the patient. At the root of this situation of mistrust lies the certainty of each party that the other does not respect his or her legitimate domain of authority, i.e., the physician does not respect the patient's authority and the patient does not respect the physician's authority. There is a flagrant mistrust of the professional's motives because of his or her refusal to allow the requested treatment, and there is also mistrust of his or her capacity to pay due respect to the patient's values and legitimate

authority, in this encounter. Secondly, the professional does not trust the patient or family's capacity to make these decisions. Not only does the professional consider having esoteric knowledge or skills sufficient to make these decisions, but he or she lacks trust in the capacity of the patient to make appropriate use of his or her values in this situation. This two-way lack of trust is illustrated by the desire of both parties to have the last say in the decision-making process.

Rather than taking sides in this debate, either for patient or professional decision-making authority, I intend to move beyond the boundaries of the futility debate and approach it from a general view of patient and professional authority. I will develop a normative conception of patient and professional authority which will allow for enhanced trust between doctors and their patients. I will do so by spelling out a conception of professional and patient authority which will help define the appropriate roles of each and establish grounds for mutual trust and respect. Patient and professional authority are interconnected in such an intimate way that they cannot be legitimately exercised if they are estranged from each other. There should be no conflict between patient authority and professional authority, if they are properly conceived; however, the current futility debate has been hampered by an exclusive focus on unilateral decision-making, at the expense of obscuring the legitimate domains of patient and professional authority in this relationship. My aim is to provide an alternative conception of decision-making based on more adequate philosophical notions of authority and autonomy.

My model of physician and patient authority is not restricted to the futility context. It can be applied as a fundamental model of decision-making within the doctor patient relationship. This model is similar to, and draws upon, the important work of The President's

Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research and of Professor Jay Katz. They too emphasize the preferability of a shared decision-making approach to the doctor-patient relationship and the avoidance of unnecessary conflict. Their models were developed within the framework of determining a valid informed consent, which preceded the futility debate. However, both the Commission and Katz argue, within the context of informed consent, that the patient should be the ultimate decision-maker. My position goes beyond them in that I develop the idea that physician and patient authority, if properly conceived, can be complementary. To articulate this, I develop a specific threefold classification of the components of patient and physician authority, which is a new way of approaching this debate.

The President's Commission and Katz do not explicitly call their models of shared decision-making a preventive approach, but they have certainly laid the ground work for subsequent models. There is however, some recent literature on a preventive approach to medical futility decisions and end-of-life decision making in general.¹¹ These approaches have developed concurrently with this thesis, so I have not drawn upon them to any significant extent.

At the outset, it must be noted that concerns about medical futility often add a third type of decision-maker to the doctor-patient relationship. In a lot of cases the patient is

¹¹Doukas, D., and McCullough, L., "A Preventive Ethics Approach to Counselling Patients About Clinical Futility in the Primary Care Setting," *Archives of Family Medicine*, Volume 5, (December, 1996), pp.589-592. Chervenak, F., and McCullough, L., "Preventive Ethics and End-of-Life Decisions," *Women's Health Issues*, Volume 6, Number 5, (September/October 1996), pp. 304-306. McCullough, L., "Preventive Ethics, Professional Integrity, and Boundary Setting: The Clinical Management of Moral Uncertainty," *The Journal of Medicine and Philosophy*, Volume 20, (1995), pp. 1-11.

incapable of participating in the decision-making process and as a result a substitute decision-maker is usually involved. If the patient has an advanced health care directive, then a proxy decision-maker is usually named. However, if there is none then the task of determining who should make substitute decisions is more difficult.

My intention in this thesis is not to address the difficulties associated with appointing substitute decision-makers when there is no advanced health care directive, although the problem is acknowledged. I will work from the assumption that the patient can participate in making decisions and if he or she is incapable of participating, then a suitable substitute has been found and that person is entitled to make decisions and have them respected as if it were the patient who was deciding himself or herself. Throughout this thesis, I refer to the conflict between the doctor and the patient, between patient autonomy and professional paternalism, and it should be understood to include the substitute decision-maker as well. Some of the case studies, in this thesis, will illustrate this point.

Chapter One Informed Consent and Different Approaches to Medical Ethics

The idea that a patient must give his or her informed consent before any medical procedure or intervention is performed is fundamental to most questions concerning clinical and research ethics. In the clinical treatment setting, informed consent is an important concept when considering issues such as a patient's right to refuse medical treatment and also euthanasia, assisted suicide, the withholding or withdrawing of life-sustaining treatment, etc. In fact, the patient's informed consent is a prerequisite for any proposed medical intervention and provides the patient with the right to refuse treatment if he or she desires to do so. However, the current debate surrounding the idea of medical futility presents a serious challenge to this view. Issues pertaining to medical futility focus on whether a patient's informed consent is necessary to withhold or withdraw treatment that the attending physician has ascertained to be futile.

The principle of respect for patient autonomy is the essence of the informed consent doctrine. Informed consent is required because there are major concerns about the best way to honour the principle of respect for patient autonomy. One of the only means of insuring the principle of respect for autonomy (at least at a basic level and however inadequately) is

to require the professional to provide the patient with enough information to make an adequately informed decision. After the patient has been sufficiently informed, the principle of respect for autonomy entitles the patient to either authorize or refuse the proposed intervention. In addition to being sufficiently informed, the patient (with the help of the physician) may choose from any of the available options.

In discussions of informed consent, it is important to realize that as the doctrine presently is, it is never supposed that the patient chooses what the alternative treatments are.¹ He or she is free to choose only from the available alternatives that are designated by the professional. The patient's role and the conception of the principle of respect for autonomy are taken to require that the patient be sufficiently informed and decide whether to accept or reject the proposed options.

The distinction between choosing among the alternatives proposed by the physician and choosing among the possible (or conceivable) alternatives, is very important, and lays the groundwork for the entire "futility" debate. It seems intuitively clear that if it is the professional's prerogative to decide what the alternative treatments are, then it must also be his or her prerogative not to include treatments that he or she believes to be futile, as an alternative. However, as the following case studies (in Chapter Two) will help illustrate, occasionally the professional will want to stop prescribing a particular form of treatment, after

¹This is one of the main issues surrounding the futility debate. Does the health care professional have an obligation to offer treatments that he or she believes are futile? This issue is one that will be taken up again in Chapter Five, where Cardiopulmonary Resuscitation (CPR) is identified as a treatment that is so widely implemented and patients are so aware of its availability, that regardless of whether the professional offers it as an alternative, many patients are aware of it. Thus, choosing among the alternatives may include choosing a form of treatment that the professional has not offered.

it has been initiated, on the grounds that its continuation is futile. If this is the case, it may be the professional's prerogative to withhold a particular form of treatment (on the grounds of futility), if he or she can keep the patient and his or her family ignorant of the alternatives.² But it will not be as easy to withdraw treatment on the same grounds, i.e., that it is no longer an option or is futile. This gives rise to the familiar distinction between "negative" and "positive" rights. I define a negative right in this context is the right to refuse treatment, whereas, a positive right is the right to insist on treatment.

The distinction between "negative" and "positive" rights is one of the fundamental conceptual underpinnings of the medical futility debate. The futility debate revolves around the expressed desire of some patients to extend this "negative right" to refuse treatment into a new "positive right" to demand or insist on treatment. This would include such things as actually formulating the alternative treatments, i.e., the patient may choose cardiopulmonary resuscitation, even though the physician may not have offered it. Therefore, in order to appreciate the importance of this plight (of advocates of the principle of respect for autonomy) it is essential to investigate exactly how the idea of informed consent evolved and what its actual status is. Having done that, I will then suggest that the existing claims around medical futility raise serious concerns about the present role of informed consent and the principle of respect for patient autonomy.

²Of course it is no longer easy to keep patients in ignorance. Patients have unprecedented resources, like the Internet, which facilitate the patient's ability to become very informed about his or her diagnosis and prognosis. Further, some treatments like CPR, are so common that they are known as a default treatments which patients have come to expect unless they explicitly state otherwise.

Development of Informed Consent

There is some confusion as to what is to count as an informed consent. Some view it as simply the disclosure of risks or the signing of a consent form and others think it is giving the physician permission to do whatever he or she wants. There are still others who think that the concept has no meaning at all. With these different views in mind it is important to start with what the courts call the fundamental goal of informed consent, the principle of respect for patient autonomy.

The principle of respect for autonomy is a general principle which refers to the way an individual is treated by others. Recall the previous discussion about Kant and Mill. The principle of autonomy furnishes the individual with the right to be treated as an end and not a means only (Kant), and also provides the person with the right to be free from undue interference with one's body or liberty (Mill). In the clinical context, the principle of respect for autonomy relies on the notion that the individual is a moral agent who has unconditional worth. It is through the exercise of choice that the individual shapes his or her own life. People in general may not approve of the choices others make or how they shape their lives, but it is recognized that one cannot substitute one's own personal judgement about what is best for somebody, in place of the individual's own. Alan Goldman states the importance of the principle of respect for autonomy in the following:

Personal autonomy over important decisions in one's life, the ability to attempt to realize one's own value ordering, is indeed so important that normally no amount of other goods, pleasures or avoidance of personal evils

can take precedence.³

Within the clinical setting, the principle of respect for autonomy guarantees the competent individual's decision to forego treatment or even cure if it includes what the individual perceives to be intolerable consequences and/or risks, regardless of how warped or perverted this individual's sense of value may be from another person's point of view.⁴

The principle of respect for patient autonomy is the fundamental basis of informed consent, and currently it occupies a very robust position in ethics, but it is not the only principle at work in the doctor-patient relationship. The other principles that are usually considered are: beneficence, nonmaleficence and justice.⁵ The principle of beneficence refers to positive actions 'to help'. The principle of nonmaleficence requires that if the physician cannot help then he or she should at least do no harm. This principle acknowledges, however, that the physician may have to harm the patient in order to produce a greater benefit, e.g., chemotherapy. The best known articulation of this principle asserts 'If you cannot help, above all do no harm'. Another general principle is justice, which requires treating like cases alike and providing equal concern and respect for all involved. This also includes obligations of

³Goldman, A., "The Refutation of Medical Paternalism," in Arras, J., and Steinbock, B., *Ethical Issues in Modern Medicine*, (Toronto: Mayfield Publishing Company, 1995), pp. 58-66.

⁴*President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*, (Washington, D.C: U.S. Government Printing Office, 1982), p. 65.

⁵Beauchamp, T., and Childress, J., *Principles of Biomedical Ethics 3ed*, (New York Oxford: Oxford University Press 1989), p. 409.

fairness in the distribution of benefits and risks.⁶

These various principles have been accepted in the applied ethics field and are intended to provide a general framework that can aid in resolving ethical problems; however, they are not intended to set an unquestioned standard.⁷ *The Belmont Report* in its 1978 letter to the President of the United States explains the proper role of these principles:

While the principles cannot always be applied so as to resolve beyond dispute particular ethical problems, they provide an analytical framework that will guide the resolution of ethical problems [...]⁸

Governments since the mid 1970's have tried to implement policies on informed consent, because they recognize the need to protect patients (as autonomous agents) in the clinical relationship. For example, in the United States two major Commissions made up of people from different fields have been asked to help suggest policy in this area. The first Commission was brought into being in 1974 under the National Research Act, which led to *The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research*. This Commission was limited to a 5 year term. The second

⁶Beauchamp, T., "The 'Four-principles' Approach," In Gillon, R., *Principles of Health Care Ethics*, (Toronto: John Wiley & Sons Ltd, 1994), p.3.

⁷The philosophical literature about the use of principles in health care is prolific, both on the pro and con sides. Clouser, K., "A Critique of Principlism," *The Journal of Medicine and Philosophy*, Volume 15, (1990), pp. 219-236; Toulmin, S., "The Tyranny of Principles," *Hastings Center Report*, Volume 11, Number 6, (1981), pp. 31-39; Toulmin, S., "How Medicine Saved the Life of Ethics," *Perspectives in Biology and Medicine*, Volume 25, Number 4, (1982), pp 737-750; Gillon, R., (editor), *Principles of Health Care Ethics*, (Chichester: John Wiley and Sons, 1994).

⁸*The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research. The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research* 1978. Letter dated September 30, 1978 to the President.

Commission was brought in by then President Jimmy Carter in 1979; it was called *The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research*. These Commissions consisted of scientists, theologians, philosophers and others. This interdisciplinary approach was important for the establishing of foundations for the development of practical guidelines that would help avoid the abuses that patients and research subjects suffered in the past.

After considerable debate, the first Commission discovered that it was possible to agree that the above-mentioned principles could be applied to the clinical situation. After they agreed on these principles, it was possible for them to develop recommendations. These principles are only intended to capture fundamental aspects of our moral judgements; in fact, according to Aristotle, general principles constitute “rules of thumb” that capture the best of our collective experience. They are the ones adopted by the two Commissions mentioned above, as well as by other major institutions such as the Medical Research Council of Canada, in its 1987 guidelines. They are also supported by the legal systems of most democracies.

Problems with the Principled Approach

Since this thesis revolves around the principle of respect for individual autonomy, it may seem like I am committed to the approach known as “principlism”. In my view, principles do indeed play an indispensable role in moral deliberations in bioethics, although not to the exclusion of other considerations, such as virtues of character and feelings of care and empathy. To help clarify my view, I will consider recent debates about principlism and

examine some alternatives to it. In the process, I hope to show that principles, such as the principle of respect for individual autonomy, are essential to bioethics, although I view them as sources of guidance regarding relevant values and considerations, rather than as formulas which can generate determinate results.

“Principlism” has been forced to acknowledge some very harsh but thoughtful criticisms, from recent critics. Commentators like Clouser and Gert⁹ have argued that the principled approach, or principlism, is not sufficient to achieve the goals that are professed by its proponents. One criticism is that these principles lack systematic relationships to each other and they often conflict, with no apparent formula for a resolution. Another of the objections to “principlism” is that the principles are nothing more than a list of values that are important to remember when attacking a moral problem. They may be important to remember but they have no deep moral substance and do not provide directive guidelines for moral conduct.¹⁰ This objection focusses on the lack of a systematic account of the principles and of the relationship (if any) between them.

Beauchamp and Childress, who are the main proponents of principlism, are accused of presenting their principles as “chapter headings” which are followed by lengthy discussions of the different and competing formulations of the various principles. The result, however, is that the principles do not emerge as guides to action but rather as a checklist of considerations that are relevant when reflecting on moral problems. Clouser and Gert explain:

⁹Clouser, K., and Gert, B., “A Critique of Principlism,” *The Journal of Medicine and Philosophy*, Volume 15, (1990), pp. 219-236.

¹⁰*Ibid*, pp. 219-236.

When they refer to a principle, in effect they are saying “go read the chapter on beneficence, justice, autonomy, or nonmaleficence and take all those diverse considerations into account when thinking about the situation.”¹¹

Traditionally a principle is manifested as a result of a well thought out and rigorously argued for theory. For instance, Utilitarianism exhibits the greatest happiness principle (also known as the principle of utility) which states that one should act so that he or she maximizes the greatest happiness for the greatest number.¹² This principle is derived from Utilitarianism and is the only principle that adequately reflects what the theory is about-there are no competing and/or contradictory principles advocated. Likewise, Kant’s Deontology reveals the importance of the individual and the principle of autonomy, but it does not confuse itself by advocating conflicting principles. This suggests that the principles that principlism’s proponents advocate are not really principles in any meaningful way. Clouser and Gert explain:

The appeal of principlism is that it makes use of those features of each ethical theory that seems to have the most support. Thus, in proposing the principle of beneficence, it acknowledges that Mill was right in being concerned with consequences. In proposing the principle of justice, it acknowledges that Rawls was right in being concerned with the distribution of goods. In proposing the principle of autonomy, it acknowledges that Kant was right in emphasizing the importance of the individual person. In proposing the principle of nonmaleficence, it acknowledges that Gert was right in emphasizing the importance of avoiding harming others. But there is no attempt to see how these different concerns can be blended together as integrated parts of a single adequate theory, rather than disparate concerns

¹¹*Ibid*, pp. 219-236.

¹²Mill, J.S., *Utilitarianism*, in Acton, H., *Utilitarianism, Liberty, Representative Government: Selections from Auguste Comte and Positivism*, (J.M. Dent and Sons Ltd.: London, 1972), p.6.

derived from several competing theories.¹³

A second objection is that the principles lack systematic unity since there is no moral theory that unites them or reveals the relationship between the principles.

In principlism each discussion of a “principle” is really an eclectic discussion that emphasizes a different type of ethical theory, so that a single unified theory is not only not presented, but the need for such a theory is completely obscured.¹⁴

The user of principlism is provided with no specific guidance. He or she is simply given a number of “insights,” “considerations,” and “theories” and is told to use them however he or she sees fit. The result is that principlism defaults to eclectic, ad hoc theories which confuse our moral reasoning.¹⁵

Critics argue that the way these principles are presented is that they can simply be applied to a bioethical problem in place of a fully developed moral theory. However, these principles are taken from different and often incompatible theories. Utilitarianism (beneficence) is concerned with consequences of actions, whereas, Kant (autonomy) is concerned with intentions and the rights of individuals despite the consequences. Regardless of whether these two theories are completely incompatible their compatibility is not made clear from the principled formulation. The point is that since these principles are derived, in some form, from incongruous moral theories the onus is on the proponents of principlism to explain a systematic relationship between them. Clouser and Gert explain:

¹³Clouser, K., and Gert, B., “A Critique of Principlism,” *The Journal of Medicine and Philosophy*, Volume 15, (1990), pp. 219-236.

¹⁴*Ibid*, pp. 219-236.

¹⁵*Ibid*, pp. 219-236.

This actually amounts simply to thinking about the case from diverse and conflicting points of view. By “applying” the “principles” of autonomy, beneficence, and justice, the agent is unwittingly using several diverse and conflicting accounts rather than simply applying a well-developed unified theory. It is risky to be doing the former while believing one is doing the latter.¹⁶

A third objection is that in many clinical situations the principles may come into conflict. For instance, the frequent conflict between beneficence and autonomy has been labelled by Ruth Macklin as the “basic dilemma of bioethics.”¹⁷ The criticism is that principlism has no formula for resolving these types of conflicts. Thus, once again the user of principlism is left to his or her own discretion as to which principle to give preference to when there is conflict.

Reply to Critics of Principlism

I wish to consider the second and third objections first and then respond to the first objection last. To explain how to resolve the dilemma of when principles conflict defenders of principlism usually invoke the arguments developed by W.D. Ross.¹⁸ Ross claims that there are many valid moral principles that reflect our ordinary moral convictions and beliefs. Unlike Kant and Mill, however, Ross does not believe that there is any one overarching principle. Kant would claim that the categorical imperative is the leading principle, whereas,

¹⁶*Ibid*, p. 223

¹⁷Macklin, R., *Enemies of Patients*, (New York, Oxford: Oxford University Press, 1993), p. 238.

¹⁸Ross, W.D., “The Right and the Good,” (Oxford: Clarendon Press, 1930).

Mill would claim that it is the principle of utility that is foremost. However, Ross was willing to accept many principles, including the ones we have been talking about, and he had no reservations about potential conflict. He admitted that principles could come into conflict and that no philosopher or professional code has successfully developed a system of moral rules that would be free of conflict.¹⁹

Conflict is resolved, according to Ross, through a weighing and balancing of the principles. This also explains the relationship between the principles. He claimed that when principles conflict we must find “the greatest duty” which is done through weighing and balancing.

Ross sought to give as much precision as possible to his ideas through a fundamental distinction between *prima facie* duties and *actual* duties: “Prima facie duty” refers to a duty always to be acted upon unless it conflicts on a particular occasion with an equal or stronger duty. A prima facie duty is always right and binding, all other things being equal. Although a firm duty, it is nonetheless conditional on not being overridden or outweighed by competing moral demands. One’s actual duty, then, is determined by the balance of the respective weights of the competing prima facie duties.²⁰

A helpful example to illustrate this point is the prima facie duty not to lie. One could argue that not lying is a prima facie duty unless some equal or stronger moral consideration conflicts with it and indicates that the specific context of this situation requires the individual to lie. The classic example of this is the “Nazi” who asks the “Jewish Sympathizer” if he or she knows where any “Jews” are hiding. In this case the individual probably has an actual

¹⁹Beauchamp, T., and Walters, L., *Contemporary Issues in Bioethics*, 5ed (Boston: Wadsworth Publishing Company, 1999), p.24.

²⁰Appelbaum, P., Lidz, C., and Meisel, A., *Informed Consent: Legal Theory and Clinical Practice*, (New York: Oxford University Press, 1987), p.17.

duty to lie and say “No.” The point is that the particular context of the situation would modify the prima facie duties and help in the weighing and balancing, this is called specification.

This concept of specification speaks to the first objection to principlism; namely, that the principles are nothing more than “chapter headings.” Beauchamp explains this process of specification of principles:

In light of indeterminacy at the heart of principles, I follow Henry Richardson in arguing that the specification of principles and related rules involves a filling in of details so as to overcome apparent moral conflicts. The process of specification is the progressive, substantive delineation of principles, pulling them out of abstractness and making them into concrete rules.²¹

An analogy for this type of specification and weighing and balancing is our legal system. A judge has certain legal principles and precedents that he or she is guided by but often these can conflict. This requires the judge to collect sufficient information (specification) in order to weigh and balance the pro’s and con’s of each alternative, so that he or she can resolve the conflict. For the sake of clarity, I will conclude this section with an example from the informed consent literature which illustrates this type of process.

A seventy-three-year-old man was terminal in the hospital and he required mechanical respiration.²² Although he had been judged competent, his request to have the respirator disconnected was refused. He even disconnected it himself, but the hospital staff reconnected him. The situation eventually went to court. The patient asserted that he had “autonomy”

²¹Beauchamp, T., “The ‘Four-principles’ Approach,” in Gillion, R., *Principles of Health Care Ethics*, (New York: John Wiley & Sons, 1994), pp 3-12.

²²Appelbaum, P., Lidz, C., and Meisel, A., *Informed Consent: Legal Theory and Clinical Practice*, (New York: Oxford University Press, 1987), p.17.

rights and that the professionals could not impose treatment on him, a competent patient, against his wishes. However, the health care professionals argued that they had a duty to preserve life and prevent suicide. The conflict was the tension between the duty to respect a competent person's autonomous wishes and the duty to preserve life. Both appear to be *prima facie* duties. "In a complicated balancing of the conflicting obligations, the court concluded that the patient's choice should be overriding because considerations of autonomy were here (though not everywhere) weightier. The court reasoned that the cost to the individual of refusing to recognize his choice in a circumstance of terminal illness could not be overridden by the duty to preserve life."²³

In conclusion, the "Principled" approach to moral guidance can be useful in directing an inquiry into competing moral claims. The lack of a theory which systematizes the various principles is not a fatal criticism. It simply requires us to be open to entertaining other aspects of a problem that appear to fall between the cracks of the principles. It is entirely possible that no such systematic theory exists. That is, there may not be any set of statements that have the status of "axioms" of a theory that imply other statements about what we ought to do in a specific case. In the meantime, in a practical or pragmatic vein, we have to work with what we have; what we have is a set of reasonable assumptions about what is important to the moral life which provides us with some guidance. We should not give these assumptions up too quickly, at least not in the absence of a viable competing approach. I now turn to briefly consider some alternatives offered to the principled approach.

²³*Ibid*, p.17.

Virtue Ethics

According to Aristotle there are two types of virtues, namely intellectual and moral. The intellectual virtues can be learned or taught, whereas, the moral virtues develop as the result of habit. Virtues are not innate moral qualities. For instance, Kant would say that the moral law is a priori, whereas, for Aristotle virtues are a posteriori in the sense that we can only develop virtues by practising virtuous behaviour. He explains the emphasis on experience:

For the things we have to learn before we can do them, we learn by doing them, e.g., men become builders by building and lyre-players by playing the lyre; so too we become just by doing just acts, temperate by doing temperate acts, brave by doing brave acts.²⁴

However, upon initial investigation it appears that the claim that virtue develops as a result of the habits that individuals form is circular. If the just man is just because he performs just actions and he performs just actions because he is a just man, then there is an apparent circularity in reasoning. The problem is that virtue requires acting in a certain way, so why does the person act in a virtuous way? Is he or she already virtuous? If so then there is no need for the action. But Aristotle anticipated this objection and explained:

Actions, then, are called just and temperate [virtuous] when they are such as the just or the temperate man would do; but it is not the man who does these that is just and temperate, but the man who also does them as just and temperate men do them. It is well said, then, that it is by doing just acts that the just man is produced, and by doing temperate acts the temperate man;

²⁴Aristotle, "Virtue and Moral Character, from *Nicomachean Ethics*, Book II, Chapters 1-9, translated by W.D. Ross (Oxford, England: Oxford University Press, 1925). In Hooke A., *Virtuous Persons, Vicious Deeds: An Introduction to Ethics* (Mayfield Publishing Company: California), pp. 169-178.

without doing these no one would have even a prospect of becoming good.²⁵

Aristotle's point is that people can perform just or temperate actions by mistake or infrequently and this does not make them virtuous. Rather the person must perform these actions consistently and out of habit. The virtues are states of character which must be nurtured over time and developed.

The primary way of determining a virtuous act is to judge whether it is performed according to the "golden mean." In other words, virtues are the mean between excess and deficiency, courage is the mean between behaving like a coward and foolhardiness, temperance is the mean between self-indulgence and self-denial. Aristotle's point is that virtues are destroyed by excess and deficiency, and preserved by the mean. But, this mean is relative to each individual. Aristotle uses the example of eating: different individuals require different amounts of nutrition and hydration. Therefore it is necessary to determine the mean for each individual in a relative sense. Likewise, in morality different people will have different thresholds for their virtues, for instance, the threshold to determine a soldier's courage is probably different from the threshold required to determine a musician's. And the threshold within the groups of soldiers and musicians will also be relative to each individual.

Aristotle cautions that achieving the golden mean is not automatic and it will take time to develop the judgment, skill and other necessary abilities. He says:

Hence also it is no easy task to be good [virtuous]. For in everything it is no easy task to find the middle, e.g. to find the middle of a circle is not for every one but for him who knows; so, too, any one can get angry—that it is easy—or give or spend money; but to do this to the right person, to the right extent, at the right time, with the right motive, and in the right way, that is not for every

²⁵*Ibid*, p. 173

one, nor is it easy; wherefore goodness is both rare and laudable and noble.²⁶

Finding the mean, for Aristotle, is the job of an experienced person, and the most important feature of this experience is in perceiving things as they should be properly perceived.

This is a very important consideration and provides a plausible venue for virtue ethics to contribute to health care. Virtue ethics is concerned with the restraining or shaping of an individuals' character, that is, transforming individuals into virtuous people. This is a different approach to ethics than explaining the universal rules that individuals must follow in order to act morally or applying *prima facie* principles. In fact, many virtue theorists criticize the principled approach for putting too much emphasis on general principles which are too vague to actually resolve issues, while underestimating the sorts of virtues needed for moral judgment in particular cases. Some critics argue that the language of principles is really derived, at a more fundamental level, from considerations of character and individual motives. To say that a morally good or virtuous action was done from principle is really to say that one approves of the motive or virtue of the actor.

Various writers in practical ethics have also argued that the attempt in a principle-based account to make obligations, codes, or procedures paradigmatic will not improve decisionmaking and conduct in the professions, because the only reliable protection against unacceptable ethical behaviour is good character.²⁷

As Beauchamp correctly points out, many defenders of virtue ethics argue that these two theories, virtue ethics and principlism, are competing approaches to ethics. However,

²⁶*Ibid*, p.177.

²⁷Beauchamp, T., "The Role of Principles in Practical Ethics", in Sumner, W., and Boyle, J., (eds) *Philosophical Perspectives on Bioethics*, (Toronto: University of Toronto Press, 1996), pp79-94.

I think there are plausible reasons to consider these as complementary approaches. When Beauchamp argues that the principles are *prima facie* duties or obligations he is admitting that there are exceptions to each principle and that they are nonfoundational. By this Beauchamp means:

A moral principle can be overridden if it encounters a contingent conflict. There are exceptions to all principles, each of which is merely *prima facie*. [...] No principle or set of ordered principles provides the sole foundation on the basis of which all other rules or judgments are supported and receive their justification.²⁸

If we accept that there are exceptions to principles and that they are nonfoundational then of course one must have some mechanism for guiding his or her judgment along with the use principles. On Ross's model of *prima facie* obligations it is possible for principles to conflict and the relationship between them is constantly changing. This is where I see virtue ethics as complementing principlism. Virtue ethics is very concerned with the individual learning how to utilize his or her judgment in a "virtuous" way. This is exactly what is required of health care professionals, they are continuously confronted with subtle and very complicated moral problems. I contend that the virtue ethicists are correct when they say that the only "reliable protection against unacceptable ethical behaviour is good character." In the sense of the Aristotelian example of the challenges that face the person who is trying to find the "golden mean," the health care professional applying principles has to use his or her judgment in much the same way. According to virtue ethics, the experienced person who has learned to perceive things properly will know how to apply the right principle or principles

²⁸*Ibid*, pp. 79-94

to a situation.²⁹ Therefore, virtue theory has something productive to contribute to this endeavour of learning to use judgment. Therefore, I suggest that virtue ethics may be most properly understood as supplementing principlism rather than replacing it.

Feminism

The feminist approach to philosophy, and ethics in particular, is primarily concerned with the oppression of women as a group. It claims that there is overwhelming empirical evidence which conclusively demonstrates that women suffer oppression and are not given equal status to men. Consider for instance what Weitzman reports:

In the United states and Canada, the extent of job segregation in the lowest-paying occupations is increasing. Indeed, if present trends continue, all of the people below the poverty line in America in the year 2000 will be women or children.³⁰

Regardless of whether this report and numerous others³¹ are accurate, the majority of feminist philosophers rest their approach, to ethics, on the premise that women suffer from oppression. They claim that this type of systematic oppression is so extensive, familiar, and

²⁹Anagnostopolous, G., *Aristotle on the Goals and Exactness of Ethics*, (Los Angeles: University of California Press, 1995), pp 305-307.

³⁰Weitzman, L., *The Divorce Revolution: The Unexpected Social and Economic Consequences for Woman and Children in America*, (Free Press: New York, 1985), p.350.

³¹For other examples refer to Kymlicka, W., *Contemporary Political Philosophy: An Introduction*, (Clarendon Press: Oxford, 1990); Sherwin, S., *No Longer Patient: Feminist Ethics and Health Care Ethics*, (Temple University Press: Philadelphia, 1992); or Walker, M. U., *Moral Understandings: A Feminist Study in Ethics*, (Routledge: New York, 1998); these have many compelling examples of the oppression of women.

entrenched in our thoughts and habits that it is very easily overlooked. The oppression that women suffer is not as simple as being excluded from the work force or treated unequally in society, it is much more entrenched in our everyday lives. For instance, many jobs in the workforce require that the candidate not be the primary caregiver of preschool children. Since it is mostly women who fall into this category they are at an automatic disadvantage for this type of employment. Of course most jobs do not publish this requirement as part of the job competition, but in order to perform the job adequately, the individual must be available when the job requires. This is often incompatible with being the primary care giver of preschool children.

It is important to note that this type of oppression is not based on some arbitrary form of discrimination where the person is excluded merely because she is a woman, but it is based on some type of sexual inequality. The fact that the system is designed in this way reflects the sentiment that women have been excluded from the beginning. Janet Radcliffe Richards explains this point as follows:

If a group is kept out of something for long enough, it is overwhelmingly likely that activities of that sort will develop in a way unsuited to the excluded group. We know for certain that women have been kept out of many kinds of work, and this means that the work is quite likely to be unsuited to them. The most obvious example of this is the incompatibility of most work with the bearing and raising of children; I am firmly convinced that if women had been fully involved in the running of society from the start they would have found a way of arranging work and children to fit each other. Men have had no such motivation, and we can see the results.³²

Dr. Sue Sherwin explains that a “feminist consciousness” is required in order to detect

³²Radcliffe Richards, J., *The Sceptical Feminist: A Philosophical Enquiry*, (Routledge & Kegan Paul: London), pp. 113-114.

this types of systemic oppression and that once one learns to interpret reality in this way one will never be fooled by the system again.³³ The feminist consciousness is, in a rudimentary sense, learning to see the oppression of women as it is currently manifesting itself (incognito) in society. Without the feminist consciousness the forms of oppression that women suffer are not at all clear, but according to the feminist they are nevertheless very real. Therefore, once one learns to approach the world through the spectacles of the “feminist consciousness” these formerly concealed truths are revealed to the observer.

There are a number of different schools of feminist thought, but the uniting impetus of the feminist movement concerns detecting and eliminating the oppression of women. Some of the different branches of feminism are: liberal feminism, social feminism, and radical feminism, to name only a few.³⁴ Sue Sherwin defines each as follows:

[...] liberal feminism is committed to making the formal legal and political changes necessary to guarantee women rights that are equal to those of men, including rights to education and to all opportunities.³⁵

Social feminism has several different features:

[Socialist feminists] insist that we attend to the structures of economic organization in oppression. Socialist feminists have shown that capitalism and patriarchy are interdependent forms of oppression in the West, which must be attacked jointly. [...] [Social feminists] critique [...] the common liberal feminist view that persons, considered in some abstract, ideal form, should be regarded as the basic units of political and moral analysis. On the socialist feminist view persons and their relationships are understood to be socially constructed. They exist in specific circumstances at specific times and places,

³³Sherwin, S., *No Longer Patient: Feminist Ethics and Health Care Ethics*, (Philadelphia: Temple University Press, 1992), p. 34.

³⁴*Ibid*, p. 27.

³⁵*Ibid*, p. 28.

and therefore sweeping generalizations about generic, ahistorical persons are problematic [...] Socialist feminists argue that it is important to look for the historical roots of the oppression that women now experience.³⁶

Radical feminism according to Sherwin focuses on sex differences and claim that sex differences function explicitly as power differences in society. The radical feminists claim that the power structure of current male-dominated society exaggerates the differences between men and women in an attempt to keep women oppressed. Sherwin says:

Because dominance structures demand dichotomies, natural differences are exaggerated and embellished; this allows the more powerful group to distinguish itself from the other, claiming not only differences but superiority and hence a legitimate right to dominate. To justify the hierarchy, differences must be established and emphasized.³⁷

Feminist approaches to philosophical ethics offer an alternative to the principle-based theories of morality and their idea of impartial beneficence in decision-making. For instance, Kant's deontological approach to ethics requires the individual to act out of a sense of duty or reverence for the moral law and to always treat people as end in themselves and to act according to the maxim that can be universalized. The utilitarians require individuals to act so that the consequences of their actions will maximize the greatest happiness for the greatest number, or at least, on some conceptions, not diminish it. In addition Rawls would insist that a theory of justice could stem from heads of families making decisions under the veil of ignorance. From these types of traditional theories we get universal principles like the principle of respect for autonomy, the principle of utility, justice, etc. Feminist ethics reject this approach and claim the following:

³⁶*Ibid*, p. 29.

³⁷*Ibid*, p. 30

Caring, empathy, feeling with others, being sensitive to each other's feelings [...] all may be better guides to what morality requires in actual contexts than may abstract rules of reason, or rational calculation, or at least they may be necessary components of an adequate morality.³⁸

Standard feminist approaches to ethics require the rejection of general appeals to the idea of justice. Kymlicka explains that traditionally the idea of justice appears to have created a distinction between private and public domains of society.³⁹ "Private" usually refers to the family unit and customary claims like 'a man's home is his castle'; "public" is the realm outside of the family unit where different families and heads of families interact with each other in commerce, politics, etc. Of course, the private realm was, and is, largely unregulated. The principles of justice applied only to public interactions which were dominated by men. Women were excluded and limited to the home or the private domain. The point is that if the principle of justice does not apply to the private domain, where women suffer tremendous oppression, then the principle is inadequate to address the important issues with which feminism is concerned.

Likewise, with general principles like autonomy or utility feminists are not satisfied. This distinction between the public and private has, according to some, forced women to approach ethics from a perspective with which men have traditionally thought to be unsophisticated and unphilosophical. They have been forced to focus on characteristics like: sympathy, compassion, love, friendship, etc. In other words, an ethic of care:

³⁸Rachels, J., *The Elements of Moral Philosophy 3ed*, (McGraw-Hill College: Boston, 1999), pp.166-167.

³⁹Kymlicka, W., *Contemporary Political Philosophy: An Introduction*, (Oxford: Clarendon Press, 1990), p. 248.

[Morality] is fragmented into a 'division of moral labor' along the lines of gender [...] The tasks of governing, regulating social order, and managing other 'public' institutions have been monopolized by men as their privileged domain, and the tasks of sustaining privatized personal relationships have been imposed on, or left to, women. The genders have thus been conceived in terms of special and distinctive moral projects. Justice and rights have structured male moral norms, values, and virtues, while care and responsiveness have defined female moral norms, values, and virtues.⁴⁰

These two positions of (1) an impartial beneficent observer (or justice) and (2) partial beneficent participant (or caring) form a major point of contention between feminism, and in this particular form an ethic of care, and standard traditional approaches to ethics, which focus on universal principles and appeals to rules. Beauchamp and Walters explain:

To understand this approach, consider the traditional theories' criterion of impartiality in moral judgment. This criterion of distanced fairness and treating similar cases similarly makes eminently good sense for courts, but does it make good sense of intimate moral relationships? The care perspective views this criterion as cutting away too much of morality in order to get to a standpoint of detached fairness. Lost in the traditional detachment of impartiality is attachment—that which we care about most and which is closest to us. In seeking blindness, we may be made blind and indifferent to the special needs of others.⁴¹

This type of care ethic focuses on responsibilities and relationships as opposed to rights and duties. In their well-known article called "Separating Care and Cure: An Analysis of Historical and Contemporary Images of Nursing and Medicine," Nancy Jecker and Donnie Self explain that there are two different senses of the word care that must be acknowledged. This also helps to explain how a ethic of care can contribute to clinical interactions between

⁴⁰Friedman, M., "Beyond Caring: The De-moralization of Gender," *Canadian Journal of Philosophy*, supplementary Vol. 13, (1987), 87-110.

⁴¹Beauchamp, T., and Walters, L., *Contemporary Issues in Bioethics Sed*, (Belmont: Wadsworth Publishing Company, 1999), p. 16.

health care professionals and patients.

The Oxford English Dictionary distinguishes two distinct senses of care. First, care means “a burdened state of mind arising from [...] concern about anything [...] mental perturbation”, and “serious or grave mental attention, the charging of the mind.” In the first sense, to “have a care” or “keep a care” is to be in a subjective state of concern about something. Second, care refers to “oversight with [a] view of protection, preservation, or guidance; hence to have the care of.” In this second sense, care implies an activity of looking out for or safeguarding the interests of others.⁴²

Jecker and Self designate the first sense of care as “caring about” someone. In other words, a nurse could care about his or her patient or people should care about the environment. This involves a subjective feeling on the part of the individual who has the feeling of “caring about.” The second sense of caring is “caring for.” This sense of caring is referred to when one says that the nurse is caring for your mother or the mechanic is caring for your car.

Feminist ethics subsumes the idea of an “ethic of care” and focuses on being a partial beneficent participant who is concerned with the particular context of a relationship and moral interaction. The “ethic of care” presents a unique challenge to “principlism” by claiming that one should abandon the requirement to seek moral principles that will have universal applicability and replace them with moral agents who have developed particular moral dispositions that will help them seek responses that are most appropriate to the particular situation.

Jane Tronto says that the ethic of care involves a shift of the essential moral

⁴²Jecker, N., and Self, D., “Separating Care and Cure: An Analysis of Historical and Contemporary Images of Nursing and Medicine,” in Beauchamp, T., and Walters, L., *Contemporary Issues in Bioethics 5ed*, (Belmont: Wadsworth Publishing Company, 1999), pp.52-62.

questions away from the question, What are the best principles? To the question, How will individuals best be equipped to act morally? Being a moral person is less a matter of knowing correct principles, and more a matter of having the right dispositions, for example, the disposition to perceive people's needs accurately, and to come up with imaginative ways of meeting them.⁴³

An ethic of care is very concerned with how a person becomes equipped to act morally as opposed to how a person decides which principles he or she will follow. At a superficial level this is an accurate criticism of principlism because principlism does require some level of impartiality, which the feminist (care ethics) would reject. But Blum presents a much deeper interpretation of principlism which indicates that there may not be as sharp a divide between care ethics and principlism as one would think:

While justice involves applying correct principles, what it takes to bring such principles to bear on individual situations involves qualities of character and sensibility which are themselves moral and which go beyond the straightforward process of consulting a principle and then conforming one's will and action to it.⁴⁴

Consider, for instance, the judge example in the previous section on principlism. In this case, the judge made an explicit appeal to the specific context that this legal/moral dilemma was situated within. In this case he was sensitive to the particular needs presented and was not solely preoccupied with the intellectual task of identifying or applying principles, although he did this too. Thus, Kymlicka explains that principles require a certain level of objectivity and impartiality but not to the exclusion of other relevant requirements.

⁴³Kymlicka, W., *Contemporary Political Philosophy: An Introduction*, (Oxford: Clarendon Press, 1990), p.265.

⁴⁴Blum, L., "Gilligan and Kohlberg: Implications for Moral Theory," *Ethics*, Volume 98, Number 3, (1988), pp 472-491.

Even if justice involves applying abstract principles, people will only develop an effective sense of justice if they learn a broad range of moral capacities, including the capacity for sympathetic and imaginative perception of the requirements of the particular situation.⁴⁵

Of course, if principlism requires that the individual acquire and utilize these broader capacities then perhaps these 'broader capacities' are more important than principles. These broader moral capacities, that help the individual apply universal principles, could in effect render such principles unnecessary. The thrust of this objection is that it is better to seek responses that are appropriate to the particular situation than to attempt to solve problems by applying universal principles. However, it is not always clear that simply analysing the specific situation while paying patient and meticulous attention to detail will be sufficient to resolve the situation. For instance, in the case of a Jehovah's Witness who refuses blood products, simply paying attention to detail will not provide a solution that deems the principle of respect for patient autonomy irrelevant. In this type of case we would have the physician's responsibility to provide care for his or her patient and also his or her responsibility to respect the patient's competent autonomous wishes. Thus, Grimshaw explains the relevance of principles as follows:

[...] principles are not instructions to avoid examining the particulars, but rather are instructions about what to look for. Unlike 'rules,' such as the ten commandments, which are intended as guides that can be applied without much reflection, a principle functions quite differently. It serves precisely to invite rather than block reflection, for it is a general consideration which one deems important to take into account when deciding what is the right thing to

⁴⁵Kymlicka, W., *Contemporary Political Philosophy: An Introduction*, (Oxford: Clarendon Press, 1990), p.266.

do.⁴⁶

In concluding this section I think that it is far too early to evaluate the feminist and *care* approach to ethics. Although I do think that the ethics of care is promising in the debate over principlism because it illuminates the necessary features of the human aspect of illness that the dominant theories overlook. Nevertheless, a theory needs time to be developed and to be articulated by its advocates. It would be premature to either reject or adopt it at this stage of its development. However, I would point out that an ethic of care, at least as developed by Jecker and Self and applied in the context of nursing, illustrates one important fact. As they apply an ethic of care to nursing, notice that it is implicit that they are in fact adopting a principled approach. For instance, when the American Nursing Association attempts to identify what their profession exemplifies, one will find declarations such as “the fundamental principle of nursing practice is respect for the inherent dignity and worth of every client,” and “the nurse recognizes those situations in which individual rights to autonomy in health care may be temporarily overridden.”⁴⁷ Surely this is “principlism” under anyone’s definition of that term. At this point I think that an ethic of care should be seen as supplementing rather than replacing principlism and that they should be seen as mutually reinforcing rather than competing approaches.

⁴⁶Grimshaw, G., *Philosophy and Feminist Thinking*, (Minneapolis, Minn: University of Minnesota Press, 1986), p.208.

⁴⁷American Nurses Association, *Code for Nurses with Interpretative Statements*, (Washington, D.C.: 1985), in Beauchamp and Walters, *Contemporary Issues in Bioethics* 5ed, (London: Wadsworth Publishing Company, 1999), p. 41.

Summary

It is clear that different approaches to bioethical issues are possible. However, we do not need to wait, in making practical decisions, for “the one true theory” to emerge. Decisions must be made on the basis of the best evidence available to us and according to the best arguments that can be mustered. Following Aristotle, we should not expect more precision than the subject matter permits:

Our discussion will be adequate if it has as much clearness as the subject-matter admits of, for precision is not to be sought for alike in all discussions.... [w]e must be content, then, in speaking of such subjects and with such premises to indicate the truth roughly and in outline, and in speaking about things which are only for the most part true and with premisses of the same kind to reach conclusions that are no better.⁴⁸

We do, however, expect people who participate in applied ethics to be willing to abide by the rule of reason. As J.S. Mill has remarked:

There is no difficulty in proving any ethical standard whatever to work ill, if we suppose universal idiocy to be conjoined with it; but on any hypothesis short of that, mankind must by this time have acquired positive beliefs as to the effects of some actions on their happiness; and the beliefs which have thus come down are the rules of morality for the multitude, and for the philosopher until he has succeeded in finding better.⁴⁹

Informed Consent

⁴⁸Aristotle, *Nicomachean Ethics*, Bk. I, in Barnes, J., *The Complete Works of Aristotle: The Revised Oxford Translation*, (New Jersey: Princeton University Press, 1985), p.1730.

⁴⁹Mill, J.S., *Utilitarianism*, in Acton, H., B., *Utilitarianism, On Liberty, and Considerations on Representative Government*, (London: J.M. Dent & Sons Ltd, 1972), p. 22.

The debate surrounding informed consent originates in the conflict between the principle of respect for patient autonomy and the principle of professional paternalism. The foundation of informed consent is respect for patient autonomy but the attitude of the traditional health care professional has been paternalistic. The idea of professional paternalism consists of the physician unilaterally deciding what is in the best interest of the patient.⁵⁰ The physician bases this decision on his or her special knowledge of medicine and on the assumption that this esoteric knowledge enables him or her to know what is best for the patient. Physicians throughout history have maintained that patient's best interests are served by following doctors orders.⁵¹ Therefore, the aim of the paternalistic physician is to ensure that the patient receives the medical interventions that will promote his or her best interest (according to the physician's conception of the patient's best interests).

As a result of these diametrically opposed positions, the question will ultimately arise concerning how a final decision should be reached. Should the professional make the decision or is it the patient who should ultimately decide? Robert Veatch⁵² and other advocates of autonomy argue that in relation to informed consent the principle of respect for patient autonomy should prevail and that it should be the patient who ultimately decides.

Informed consent emerged as a legal question because of an understanding that the

⁵⁰Emanuel, E., and Emanuel, L., "Four Models of the Physician-Patient Relationship," *Journal of the American Medical Association*, Volume 267, Number 16, (April 1992), pp. 221-226.

⁵¹Katz, J., *The Silent World of Doctors' and Patients'*, (New York: Free Press 1984), p. 86.

⁵²Veatch, R., "Why Physicians Cannot Determine if Care is Futile," *Journal of the American Geriatrics Society*, Volume 42, Number 8, (1994), pp. 871-874.

principle of respect for patient autonomy requires the physician to provide the patient with sufficient information to make an informed decision. Courts realized that this principle cannot be satisfied by simply allowing the patient to say "yes" or "no" to a proposed procedure. They understood that occasions arise in which a patient claims that he or she has suffered damage as a result of not having sufficient information. In other words, if the person had known all of the relevant facts about the intervention prior to its implementation, the person would not have authorized the procedure or consented to it. At a minimum, the individual asserts that he or she was entitled to more information about the procedure and any alternatives before it was implemented. This would have provided the patient with the opportunity to act autonomously.

What follows is a history of the informed consent doctrine as it developed through the courts. My purpose is to show how this doctrine has developed and the extent to which Courts were willing to go in support of patient autonomy and the right to refuse treatment.

From this we will see that the present issue of medical futility challenges the doctrine of informed consent because treatment options will not even be presented to the patient for his or her consideration on the grounds that the treatment is considered "futile" by the physician. The concept of medical futility is the latest manifestation of the age-old struggle between doctors and their patients to claim superiority of knowledge and to establish, maintain, or capture decision-making authority in the doctor-patient relationship.

The Roots of Informed Consent

The *Salgo* case of 1957⁵³ gave birth to the notion of informed consent. It was the first case to use the term, although the idea of respect for patient autonomy in law can be detected as early as Judge Cardozo's 1914 statement which articulates this basic principle:

... every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.⁵⁴

However, despite *Salgo* 1957 and Cardozo's 1914 position, medical practice has adhered to the idea of professional paternalism. Paternalism is in direct conflict with the idea of respect for the principle of autonomy that Judge Cardozo articulated. Hippocrates stated his paternalistic instructions to physicians in the following terms:

Perform [these duties] calmly and adroitly, concealing most things from the patient while you are attending to him. Give necessary orders with cheerfulness and sincerity, turning his attention away from what is being done to him; sometimes reprove sharply and emphatically, and sometimes comfort with solicitude and attention, revealing nothing of the patient's future or present condition.⁵⁵

Before the introduction of the notion of "informed consent," "consent" simply consisted of the doctor revealing to the patient the nature of the procedure and receiving permission to perform it. The physician was selective in what he or she told the patient

⁵³*Salgo v Leland Stanford Jr. Univ. Bd. of Trustees*, Cal. App. 2d 560, 317 p.2d 170 (1957).

⁵⁴*Schloendorff v New York Hospital* 105 N.E. 92 (N.Y. 1914), p. 526. In Katz, J, *Experimentation With Human Beings: The Authority of the Investigator, Subject, Professions, and State in the Human Experimentation Process* (New York: Russell Sage Foundation, 1993), p. 526.

⁵⁵*President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship, Volume 1*, p. 32.

because informing the patient was not the goal; the goal was to get the patient to assent to what the physician thought was in the patient's best interest.

A disturbing example of consent that is not informed is the following case of a man who went to the doctor complaining of a slight pain in his leg.⁵⁶ He was having muscle spasms at night and found it difficult to sleep. The doctor recommended surgery and the man consented. However, during the surgery complications developed and refuse from the bad leg travelled into the man's good leg. His good leg had to be amputated and then he was put on dialysis because his kidneys failed, which was a further complication. After a few months the man died. The man's wife had no idea that this could happen as a result of the operation. She asked the Royal College of Physicians and Surgeons of Canada 'how these things could happen?'. The reply was that 'these are common complications in this type of procedure'. The wife exclaimed that if she and her husband had known that these were possible risks attendant to this type of procedure, they would never have consented to the intervention.⁵⁷

This brief example helps illustrate that mere "consent" is significantly different from "informed consent." In this example the person gave consent or signed a consent form, but in a sense it was not a true consent. This was not an autonomous decision, because it was made in ignorance of the relevant facts. In order to respect autonomy, more information was needed than was provided to the patient. The attitude of the physician in this example was guided by the traditional paternalistic approach where the physician tried to do what he

⁵⁶Coy, A., "Informed Consent - The Patient's Perspective," *Health Law in Canada*, Volume 2, Number 3 (1981), p. 55.

⁵⁷*Ibid.*, p. 55.

thought was best for the patient. The bottom line is that the professional did not think that these complications would arise and therefore did not want to bother the patient by worrying him about these remote possibilities. In this type of situation the disclosure of sufficient information would have allowed the patient to make autonomous choices and would have definitely minimized the state of ignorance that this person was intentionally kept in. It is this lack of information that the notion of informed consent has tried to correct.

In this attempt to correct the lack of information the law focussed on risk disclosure. The idea was that a person's consent was not informed if information pertaining to risks which were material to the patient were not divulged. The courts imposed a duty to disclose material information on physicians and they were ultimately liable for damages if this duty were breached. The courts determined that an individual's consent was sufficiently informed if the doctor fulfilled his or her duty to disclose material information. Also, the consent could still be informed if it was established that the information the doctor withheld from the patient was not material to making a decision.⁵⁸ The formula for informed consent that emerged from the courts was that the doctor must inform the person of the nature of the proposed touching and obtain voluntary permission to do it, and reveal all information that would be material to making a decision. There must, therefore, be a discussion of possible risks and benefits of the proposed intervention. Chief Justice Bora Laskin in the *Hopp v Lepp* case of 1980 puts the duty to disclose this way:

...in obtaining the consent of a patient for the performance upon him of a surgical operation, a surgeon, generally, should answer any specific questions

⁵⁸Robertson, G., "Informed Consent Ten Years Later: The Impact of *Reibl v Hughes*," *The Canadian Bar Review*, (1991), p. 25.

posed by the patient as to the risks involved and should, without being questioned, disclose to him the nature of the proposed operation, its gravity, any material risks and any special or unusual risks attendant upon the performance of the operation.⁵⁹

A major problem that arises is to specify exactly what risks should be divulged: i.e., what is a material risk? Should a remote risk be considered and/or should risks that are inherent to all medical procedures be divulged?⁶⁰ In addition there are questions about the risks that the doctor deems altogether insignificant. Should they be disclosed as well? This quandary about risks and hazards is one of the most troublesome aspects of informed consent.⁶¹

The doctrine of informed consent raises two very important questions: first, how can it be determined that the information withheld from the patient was material to his or her decision-making process? And secondly, what charge is it appropriate to hear the litigation in? That is, does a lack of informed consent go to a battery action or to a negligence action, and what difference does it make? These are the topics I consider in the following section. Then I will discuss the various standards governing disclosure followed by an illustration of the facts and consequences of *Reibl v Hughes*.

⁵⁹*Hopp v Lepp* 2 Supreme Court Reporter, (1980), p. 210.

⁶⁰The concern here is that if a remote risk is considered as a high priority concern it is being treated unreasonably and could prevent someone from undergoing treatment that is crucial. A lot of practitioners feel that a probability of occurrence that is very low is not enough to endanger someone's well-being by raising undue concern. There is also the practical problem that practitioners feel they simply do not have time to treat remote possibilities as significant.

⁶¹Reich, W., *Encyclopedia of Bioethics, Volume 2* (New York: The Free Press, 1978), p. 767.

Battery and Negligence

Claims alleging a lack of informed consent could be heard in either battery or negligence, depending upon whether the information provided was so lacking that no real consent could be said to be given, or whether the physician was found to have fallen short in the performance of his or her duty to the patient.⁶² Where there is no consent to treatment the case will be heard in battery; however, if there is consent but some complication arises because of inadvertence or the surgery was performed unskillfully, the case would be heard in negligence. Battery is an intentional tort, whereas, negligence is unintentional or careless treatment. The courts were not clear about what charge was appropriate to use in hearing “informed consent” cases. In a situation in which a person has suffered damages because he or she was not informed of the risks, the courts had the task of determining whether the information withheld was enough to constitute a battery or if it implied that the physician was negligent in his or her conduct by not meeting the requirement of disclosing material information.

Battery

⁶²What I am considering is medical malpractice dealing exclusively with consent. Normally the case arises when a patient has suffered damages because some risk has materialized which the patient was not aware was a possibility. The practitioner did not inform the patient of this particular risk, for whatever reason. The question is whether this lack of information is significant enough to render the consent legally invalid or whether it reflects that the doctor was negligent in performing his or her duties by withholding the information. Of course, along with deciding whether the case should be heard in battery or negligence, it must also be determined whether the doctor had a duty to disclose this information in the first place.

The charge of battery is substantiated if the plaintiff has been touched by the defendant without giving his or her consent to the touching. The patient (plaintiff) need only establish that the defendant touched him or her without permission. In battery it is not necessary to establish loss as a result of the touching which makes this charge simpler for the patient to establish than a claim of negligence. A charge of negligence requires that the plaintiff suffer actual harm, whereas, a battery charge acknowledges not only physical damage but also damages to dignity and does not necessarily require the consequence of physical harm.⁶³

A battery can be committed by intentionally attempting to cause harm, regardless of how indirectly it is brought about.⁶⁴ Thus, a punch or kick would be a direct attempt at causing harm, and pulling a chair out from under someone or jostling someone rudely is an indirect attempt to harm. The contact does not have to result in harm, all that needs to be shown was that the contact was offensive.

Marcus L. Plante in his article "An Analysis of 'Informed Consent'," provides a striking example of a situation where the person was battered because of not providing enough information to the patient. In *Corn v French* the defendant surgeon discovered danger signals while examining the plaintiff's breast. The surgeon recommended removal of the breast but the patient refused, the doctor agreed and assured her that he had no intentions

⁶³For instance consider the case of a doctor who fondles a patient while the patient is under anaesthetic. There is no physical harm and the person is not even aware of the violation, however, there is clearly an injury to dignity.

⁶⁴Linden, A., "The Patient, the Doctor, and Their Duty to Communicate With One Another," *Health Law in Canada*, Volume 2, Number 3, (1981)p. 58. Linden in this article says that a battery could be committed by intentionally causing physical harm; however, the harm does not have to actually occur all that is required is that the person attempt to cause harm.

of going against her wishes but he did want to perform another examination. "When the plaintiff reached the hospital she signed a form giving consent to a 'mastectomy'. Plaintiff later testified she didn't know what the word meant."⁶⁵ The defendant explained that he was only going to perform a test, but when Mrs. Corn emerged from anaesthesia her breast had been removed. In spite of the fact that she signed a consent form giving permission for a mastectomy it is very clear that this was not an informed consent. The consent was obtained in a fashion that effectively vitiates it and renders the physician subject to a charge of battery. However, if the woman authorized the procedure (understanding the word mastectomy) but something happened that she was not aware of the situation may result in a negligence charge.

Negligence

In an action based on negligence the plaintiff must demonstrate that he or she suffered damages as a result of something the defendant did or failed to do. The plaintiff must show that if it were not for the defendant's negligence he or she would not have suffered. Negligence does not require touching: it could be the omission of something or the negligent performance of a duty.

The question is not whether the defendant conveyed a clear impression of the nature and character of the intended touching. It is assumed he did so. The question is whether the defendant violated his obligation to the patient to describe collateral consequences that might ensue as a result of the intended

⁶⁵Plante, M., "An Analysis of Informed Consent," *Fordham Law Review*, (1968), p.639.

and permitted touching, or from some other source such as the healing process.⁶⁶

The charge of battery is appropriate where there has been absolutely no consent to the physical contact in question. A claim based on negligence is correct when consent has been obtained to the procedure, in general, but certain features of this procedure were not made explicit.⁶⁷

Calculus of Negligence

The calculus of negligence requires four things: first it must be established that the doctor had a duty to disclose the information; secondly, the doctor must have breached this duty; thirdly, it must be shown that the patient suffered damages; and finally it must be shown that the breach of the duty by the doctor caused the damages suffered by the patient.

To determine whether the doctor breached his or her duty to the patient it is necessary to have a standard to which one can appeal to. Three different standards existed to serve this function; courts could use a professional standard, an objective standard, or a subjective standard. Regarding the causation problem in negligence the major obstacle is the patient's hindsight. After the fact it is difficult to determine whether the person would have been prepared to accept the risk. The patient obviously would say 'had I known I would not have consented to the procedure'. The crucial thing is whether before the procedure the person

⁶⁶*Ibid.*, p. 658.

⁶⁷Mason, L., et al., *Law and Medical Ethics*, (London: Butterworth and Co Ltd., 1983), p. 118.

would have been willing to accept the risk.

To overcome this obstacle the courts explored different theories to aid in reaching a fair decision about how to deal with the patient's hindsight. The courts devised an objective standard and a subjective standard to aid in its fact finding mission.⁶⁸ These standards were designed to decide whether the patient, if informed, would have accepted the risk(s) and undergone the procedure or deemed the risk(s) too great and chosen to forgo the procedure.

Standards of Disclosure

The professional standard dictated that the amount of information the physician was required to disclose was to be decided by the custom of the medical profession. This standard demanded that adequate disclosure be determined by the customary rules or traditional practices of the professional community.⁶⁹ The amount of information the physician was required to disclose was primarily a question of medical judgment; the standard was simply set by the profession. If it was established that the physician had a duty to disclose the particular information, the disclosure need only be equal to that which a reasonable medical

⁶⁸I will explore the standards the courts used to decide whether the physician did in fact have this duty, which is the standard of care, and whether the breach of the duty caused the damages, which is causation. The criticisms of these standards apply strictly to the informed consent debate and should be evaluated only in that context.

⁶⁹Beauchamp, T., and Walters, L., *Contemporary Issues in Bioethics 2ed*, (Belmont California: Wadsworth Publishing Company, 1982), p. 172.

practitioner would make under the same or similar circumstances.⁷⁰

The objective standard, also called the reasonable person standard, emerged in the decisions of *Canterbury v Spence*, *Cobbs v Grant* and *Cooper v Roberts*.

A fair statement of the rule that emerged is that the physician is required to disclose all information about a treatment that a reasonable person in the patient's circumstances would find material to a decision to undergo or forego treatment [...]⁷¹

The reasonable person standard demands that the information disclosed be determined by reference to a hypothetical reasonable person in the patient's position. The materiality of a particular piece of information would be determined by the importance a reasonable person would attribute to it. Thus, according to the courts, the scope of the physician's duty to disclose would not be determined by the custom or practice of the particular physician or by the medical profession in general, but by the needs of the hypothetical reasonable person.⁷²

The third standard is a subjective patient-oriented standard. This standard obligates a physician to disclose the information that the particular patient would find material to making the decision whether to undergo treatment. Thus, the standard is subjective to each patient.⁷³

Initially the courts were confused about what standard to use and further confusion

⁷⁰Appelbaum, P., Lidz, C., and Meisel, A., *Informed Consent: Legal Theory and Clinical Practice*, (New York: Oxford, 1987), p. 41.

⁷¹Appelbaum, P., Lidz, C., and Meisel, A., *Informed Consent: Legal Theory and Clinical Practice*, (New York: Oxford University Press, 1987), p. 45.

⁷²*Ibid.*, p. 45.

⁷³Appelbaum, P., Lidz, C., and Meisel, A., *Informed Consent: Legal Theory and Clinical Practice*, p. 47.

arose because the courts were uncertain about what charge to hear the litigation in, whether it should be heard in battery or negligence. It was not until the landmark Canadian case of *Reibl v Hughes* that these issues were clarified, at least in Canada.

Reibl v Hughes

Reibl v Hughes determined that the lack of information does not vitiate consent but it shows that the doctor was negligent in his or her duty to disclose material information and that the way to determine whether the doctor had a duty to disclose the information was through using the reasonable person standard.

Mr. Reibl was 44-years-old when it was discovered that he had a major occlusion in his left carotid artery. The proposed procedure was elective there was no emergency that demanded immediate attention. During or immediately after the operation, Mr. Reibl suffered a stroke which resulted in unilateral paralysis, impotence, and total permanent disablement. Unfortunately Mr. Reibl was not aware that any of these were possible complications. He was only 18 months from retirement and a lifetime pension, which demonstrated to the court that if he had known of these possible risks he would have refused surgery or, at least, have waited until after his retirement.⁷⁴

The trial judge held that Dr. Hughes (the surgeon/defendant) was liable in both battery and negligence. It was found that he was guilty in negligence because he negligently performed his duty to his patient. The duty was to disclose the information that a competent

⁷⁴*Reibl v Hughes* 14 C.C.L.T. (1980), p. 4.

medical practitioner in that situation would have disclosed, namely, the risks of paralysis and the possibility of a stroke or death. The trial judge used a professional standard to determine what information the physician had a specific duty to disclose. The court determined this professional standard through expert medical evidence. As a result of his breach of the duty to warn, it was determined that Dr. Hughes had performed his duties negligently. It was further decided, at the trial, that Dr. Hughes was also guilty of battery. The court ruled that had Mr. Reibl known of the attendant risks of paralysis and the possibility of death, he would have chosen to forgo the treatment, at least until after his retirement in 18 months. Therefore, the court decided that the lack of disclosure vitiated the consent and thus rendered the doctor guilty in a charge of battery. Damages were awarded to the plaintiff in the sum of \$250,000.

The Ontario Court of Appeal allowed Dr. Hughes' motion for appeal and ordered a new trial for damages and liability. This court then held that "there was [...] no duty upon a surgeon to inform a patient of the statistical risks of death or paralysis attaching to [the] proposed surgery."⁷⁵ Mr. Reibl then appealed to the Supreme Court of Canada where Dr. Hughes accepted the assessment of damages at the trial. Therefore, the issue was limited to the lack of disclosure of the risks of paralysis and death. The Supreme Court of Canada decided that failure to disclose certain risk does not constitute a battery but it may show that the physician performed his or her duties negligently. In other words, not disclosing particular risks would be a breach of duty if it is established that the physician did indeed have a duty to disclose that particular risk.

Reibl v Hughes decided on the reasonable person standard and determined that cases

⁷⁵*Reibl v Hughes*, p. 2.

dealing with lack of informed consent should be heard in negligence, not battery. The decision by then Chief Justice Laskin reads:

All these factors suggested that a reasonable person in the plaintiff's position would, if the surgeon's duty of disclosure had been discharged, have opted against surgery.⁷⁶

The non-disclosure of risks was not deemed sufficient to vitiate the consent and thus constitute a battery, but instead went to the charge of negligence. Presently, the reasonable person standard is used and the majority of cases are tried in negligence, unless there was no consent at all or there was misrepresentation.

The decision of *Reibl v Hughes* has not been as helpful to the plight of patient plaintiffs as might have been thought. There are three significant theoretical assertions as a result of this case which do not pay special attention to patient's autonomy. The first is about the applicable cause of action, i.e., battery or negligence. *Reibl v Hughes* dictated that if a physician fails to warn a patient of a material risk or risks which accompany a proposed procedure the proper cause of action is negligence. The Supreme Court of Canada decided that failure by a physician to disclose certain risks is a breach of duty to warn and should be heard in negligence. It does not vitiate the consent and constitute a battery. The charge of battery should be reserved for cases where there has been no consent at all or where the surgery or treatment has been performed beyond what was consented to.⁷⁷

The second important area that *Reibl v Hughes* influenced relates to the standard of

⁷⁶*Reibl v Hughes*, p. 2.

⁷⁷Robertson, G. "Informed Consent Ten Years Later: The Impact of *Reibl v Hughes*," *The Canadian Bar Review*, (Sept 1991) p. 425.

disclosure. The Supreme Court of Canada invoked a reasonable person standard and held that doctors have a duty to disclose all relevant information that a reasonable person in the patient's position would want to know. Recent commentators have argued that this is more properly labelled as an objective/subjective standard.⁷⁸

The third important doctrinal change involves the issue of causation. It must be shown that the information which the plaintiff was denied would have affected the person's decision to undergo the proposed intervention. The Supreme Court decided that causation is to be determined by an objective/subjective test of what a reasonable person in the patient's situation would have chosen to do. The decision was primarily to balance patient's hindsight and what could be required of physician's to disclose. This aspect of the *Reibl v Hughes* decision was upheld in a very recent case, published in a 1997 issue of *The Canadian Medical Association Journal*, concerning an instance of maternal chicken pox. In this case the Supreme Court affirmed the trial judge who decided that the physician's failure to disclose certain serious risks to the fetus, associated with maternal chickenpox, would not have affected the mother's decision to continue with the pregnancy, and thus there was no obligation to reveal it.⁷⁹

Despite these three important doctrinal changes initiated by the *Reibl* case, informed consent plays a relatively small role in malpractice litigation. The statistics reveal that informed consent, since 1980, is not usually the basis of a plaintiff's claim. In fact it is not an

⁷⁸Kluge, E., *Biomedical Ethics in a Canadian Context*, (Prentice Hall, 1992), p. 119.

⁷⁹Capen, K., "Supreme Court Reaffirms Landmark Informed-Consent Ruling in Chickenpox Case," *Canadian Medical Association Journal*, Volume 157, Number 5, (1997), pp 553-555.

important claim at all. "In only 13 of the 117 cases analysed (that is approximately 11%) did the plaintiff rely exclusively on an alleged failure to disclose material information."⁸⁰ Nearly all informed consent cases are brought in conjunction with a charge of negligent treatment; and it is doubtful that these cases would have been brought on the grounds of informed consent alone. It is suggested that the informed consent charge was brought merely to bolster the real claim of negligent treatment.

[...] [In 81% of the cases in which the plaintiff was successful, the defendant was found to have performed the treatment negligently. In more than half of the successful cases (56%), negligent treatment was the sole basis of liability and the informed consent claim was dismissed. This tends to suggest that informed consent is probably being used merely as an ancillary ground in negligent treatment cases, and thus in itself is having only a minor impact in the frequency of claims.⁸¹

Informed consent claims since the *Reibl v Hughes* decision were almost never successful and actually failed in 82% of the cases analysed by Robertson in his paper "Informed Consent Ten Years Later: The Impact of *Reibl v Hughes*." It is also interesting to note that Robertson points out that in 1990 and 1991 all 23 of the cases based on disclosure failed. The reason for this is the objective test for causation. In a lot of instances doctors have been absolved of liability even if it is established that he or she was negligent in performing the duty to disclose. This was because it was believed that a reasonable person would have accepted the risk(s) and gone ahead with the procedure any way.

Another problem with the causation issue is that courts believe a reasonable person

⁸⁰Robertson, G. "Informed Consent Ten Years Later: The Impact of *Reibl v Hughes*," *The Canadian Bar Review*, (Sept 1991) p. 427.

⁸¹*Ibid*, p. 427.

would not go against his or her doctor's advice.

One example of this is the growing acceptance by Canadian courts that the greater confidence and trust which a patient has in a physician, the less likely a reasonable person in that patient's position would decline treatment recommended by the physician, even if full disclosure of material risks were made.⁸²

Along with this causation problem is the claim, which is valid in most Canadian courts, that the plaintiff's acceptance of more serious risks than the one that materialized, shows that he or she would have made the same choice regardless of whether the less serious risk was disclosed or not.⁸³ Courts determined from this that acceptance of more serious risks implies that even if one were made aware of these less serious risks it would not have changed the ultimate decision. Thus, even if the doctor had a duty to disclose that piece of information he or she is not liable since a reasonable person would have accepted the risk regardless.

Informed Consent and Medical Futility

The doctor-patient relationship is perhaps among the most complicated and profound relationships in an individual's life. This relationship has generally been labelled fiduciary because it is characterized by trust on the part of the patient and a corresponding duty on the part of the professional.⁸⁴ Individuals reveal private personal information to physicians and

⁸²Robertson, G. "Informed Consent Ten Years Later: The Impact of *Reibl v Hughes*," *The Canadian Bar Review*, (Sept 1991) p. 435.

⁸³*Ibid*, p. 435.

⁸⁴Macklin, R., *Enemies of Patients*, (New York: Oxford University Press, 1993), p.

allow them to invade their bodies in very intimate and often intrusive ways.⁸⁵ Part of the reason that individuals allow physicians to touch their bodies in these ways is that the patient is either ill or injured and requires the unique skills of the physician to get well. However, this unilateral dependence renders the person vulnerable and often desperate, whereas the professional is knowledgeable and in control of the desired medical interventions. R.M Zaner explains the inequality and dependence in the following:

Not only is the sick person existentially vulnerable by virtue of being sick, but it is the physician, not the patient who has the ability and skill to help; the physician, not the patient, has access to resources (surgeons, drugs, etc.); and in modern times, the physician, not the patient, is socially legitimated and legally authorized to be a physician. As sick and in the hands of the physician, the patient is thus multiply disadvantaged.⁸⁶

The ethical implications of this relationship have been studied and debated extensively. There have been numerous policies and laws formed in an attempt to protect the patient in this vulnerable situation. Understandably, then, the principle of respect for patient autonomy and the doctrine of informed consent correctly endeavour to protect the patient and provide him or her with some decision-making power in this vulnerable situation. However, a new phenomenon has occurred which threatens the hard won position that the principle of respect for patient autonomy currently occupies. This phenomenon is referred to as “medical futility.” The concern about medical futility is that the patient and physician occasionally disagree about the proper course of treatment and whether it should be pursued. The patient may

⁸⁵For instance, a gynecological examination if not performed by a physician would be considered an act of rape, whereas, the patient authorizes the physician to invade the body in this way.

⁸⁶Zaner, R., “Justice and the Individual in the Hippocratic Tradition,” *Cambridge Quarterly of Health Care Ethics*, Number 5,(1996), pp. 511-518.

believe that the treatment is valuable and worthwhile; whereas, the professional may believe that it will not serve the interests of the patient. In the latter case these are what have come to be called *futile* treatments.

The issues surrounding futility pertain to the fact that the patient desires to be so involved in (or in control of) the decision-making process that he or she may actually want to direct treatment. This desire to direct treatment becomes particularly controversial in regard to procedures that the professional believes to be futile. Some commentators in the literature contend that the actual word “futile” is very ambiguous.⁸⁷ It is rare that the word “futile” in the clinical context means the same as in our everyday usage. More often it refers to a decision about the worth of pursuing a remote possibility of success or a decision about the quality of the patient's life. It is because of this ambiguity that some patients believe that they should be entitled to make these types of (value) judgments and not be subjected to the professional's discernment of what is best for the patient.

The whole informed consent debate reveals how important society and the courts believe the principle of respect for patient autonomy to be. The courts struggled to come up with a fair conception of this principle that would be relevant to the clinical encounter between the doctor and patient. Informed consent was a standard battle over 'turf'. Who gets to decide, the doctor or the patient? This battle has currently resurfaced in the form of medical futility and the answer to the familiar question of who gets to decide, is not as clear.

Between the era of paternalism, where the physician insisted that he or she knew what

⁸⁷Lantos, L., et al., “The Illusion of Futility in Clinical Practice,” *The American Journal of Medicine* Volume 87, (1989), pp. 81-84.

was medically indicated and what suited the patient's best interest, and the current era of patient autonomy that permits individuals to refuse physicians' medical judgment based on a personal evaluation of their own best interests, there has been a loss or obscuring of the proper domain of both patient and professional authority. Physicians traditionally believed that the esoteric knowledge of their profession was the source of their special "authority." But this is currently under attack. I want to suggest that what is going on in the futility debate is an attempt by physicians to reestablish their authority. What is at stake here is the legitimacy of their particular knowledge and the authority they want to recapture in the decision-making process. Behind the struggle about what care is futile and what should be the proper definition of futility, I suggest that there lies another battle which is perhaps subtler and less perceptible but may be more decisive in the long run. My contribution will be to bring this struggle to the forefront and to suggest how it may influence the current debate about futile treatments.

Chapter Two Medical Futility

The labelling of interventions as futile by the professional, and the prospect of the patient being refused medical treatment or having it withdrawn on these grounds, has initiated a debate among medical personnel and also philosophers, lawyers, theologians, etc., as to the meaning and usefulness of the concept of futility. One possible source of confusion is that the wide recognition of the principle of respect for autonomy had established a strong right for patients to refuse treatment. This was illustrated in the case of *Reibl v Hughes*.¹ However, this negative right to refuse treatment does not entitle patients to demand treatment, as this would require a positive right. The distinction between positive and negative rights is particularly relevant in relation to discussions about futility, because the patient (and/or family) is usually demanding a form of treatment that the professional does not think is appropriate. Consider for instance the following example: Baby K² was born with a condition known as encephalopathy. This term literally means “without a brain,” however this baby had some lower brain centres functioning such as the ones responsible for

¹Obviously Mr. Reibl should have been presented with enough information to make an informed choice about whether to pursue treatment or not.

²In the Matter of Baby K. 832 F. Supp. 1022 (E.D. Va. 1993).

controlling respiratory and other reflex functions. Despite this, Baby K, would never be conscious or able to think, see, or hear. Nonetheless, Baby K's mother obtained a court order which forced doctors to provide aggressive life-support treatment, despite professional objections that treatment was futile.³

This type of disagreement has raised major concerns about the proper role of the doctor and the patient (and/or family), in this complicated clinical relationship. To explore this issue, it will be necessary to set the stage by looking at one seminal autonomy case, that of Karen Quinlan, and then contrasting it with the paradigm futility case concerning Mrs. Helga Wanglie. The contention is that the *Helga Wanglie* case and the *Baby K* case are the ones that put the idea of medical futility "on the map."⁴

The intention is to show, using real life examples, exactly what the futility debate is about. From this it will be necessary to explain the two main conceptions of futility and then show how proponents of futility approach this issue, by assigning decision-making power to either the physician or the patient. I will then state the particular way in which I want to approach the futility debate in order to introduce a different perspective.

³The decision in *Baby K* created more confusion than anything else. Instead of addressing, head on, the idea of medical futility and providing treatment to an anencephalic infant the court relied on the plain language of the Emergency Medical Treatment and Active Labor Act of 1986. This Act was designed to prevent, US hospitals, from dumping economically disadvantaged patients. It simply states that stabilizing medical treatment cannot be denied any person who is presented at an emergency room. Baby K qualified for this and each time she was presented with breathing problems, the Act required that she be stabilized. The court did not address the issue of providing respiratory support to a anencephalic infant.

⁴Schneiderman, L., "Commentary: Bringing Clarity to the Futility Debate: Are the Cases Wrong?" *Cambridge Quarterly of Health Care Ethics*, Volume 7, Number 3,(1998), pp. 273-278

Karen Quinlan

In April 1975, Karen Quinlan⁵ (22 years old) went to a pub to celebrate with friends. At the time she was on prescription medication. This mixed with alcohol caused her to lose consciousness and stop breathing. After being admitted to the hospital, she was put on a respirator and diagnosed as in a Persistent Vegetative State (PVS), a condition marked by sleep-wake cycles and an inability to perceive or respond to communication.

After five months of extensive consultation with family, friends and clergy, the Quinlans requested that mechanical ventilation be stopped. However, hospital officials and doctors refused to honour this request, stating that such an action would be tantamount to euthanasia, which they felt to be both illegal and immoral. The Quinlans tried to obtain a court order from the Superior Court of New Jersey to force the doctors to withdraw life-sustaining treatments, but the judge refused their petition. He claimed that a court should not interfere with a doctor's decision to act in his or her patient's best interests. The Quinlans then appealed to the Supreme Court of New Jersey, which overturned the first judgment. One of the decisive factors in this case was the presentation of reliable evidence that Ms. Quinlan would not have wanted to be kept alive in a Persistent Vegetative State. The final court decision was based, therefore, not only on her best interests, but also on respect for her own wishes (autonomy).

⁵New Jersey Supreme Court, *In the Matter of Karen Quinlan, an Alleged Incompetent*. Reprinted from 70 *New Jersey Reports* 10. Decided (March 31, 1976).

This case focussed on the principle of respect for patient autonomy. Despite the professionals' opinion that treatment should be pursued and that treatment was in her best interest, the courts decided that the patient's subjective preferences, about what was in her best interests, should be respected. *Quinlan* clearly established that the individual patient is entitled to refuse treatment despite the professional's recommendation to the contrary; thus, the patient's subjective knowledge about what constituted her best interests superseded the physician's opinion. Recent developments concerning medical futility, however, present a new dilemma. The concern is not about the patient's right to refuse treatment, but about the patient's (or surrogates') right to direct medical treatment. This will be highlighted in the following case concerning Mrs. Helga Wanglie.

Mrs. Wanglie and The Futility Debate

On January 1, 1990, Mrs. Helga Wanglie, then age 85, was admitted to the Hennepin County Medical Centre, requiring emergency treatment of dyspnea from chronic bronchiectasis.⁶ Upon admission, the hospital staff performed an emergency intubation and put her on a respirator. At this point she was conscious and could acknowledge family members and indicate when she was uncomfortable. In May, she was discharged to a chronic care hospital after repeated attempts to wean her from the respirator had failed. However, one week after being admitted, her heart stopped during a weaning attempt. Hospital staff

⁶Miles, S., "Informed Demand for "Non-Beneficial" Treatment," *New England Journal of Medicine*, Volume 325, Number 7 (August 15, 1991), pp. 512-515.

resuscitated her and transferred her to another hospital for intensive care, where she remained unconscious. The attending physician recommended, to her family, that life support be stopped and she be allowed to die. However, they refused and transferred her back to Hennepin County Medical Centre, where she was diagnosed as in PVS, as a result of severe anoxic encephalopathy.

During the following months, Mrs. Wanglie's physician, the nursing staff and a consulting ethicist recommended that treatment be stopped. The family again refused, and insisted on continued treatment, providing the following four reasons for their decisions: (1) physicians should not play God, (2) she was not better off dead, (3) removing life support showed moral decay in our civilization, and (4) they hoped for a miracle.

By December of 1990, the medical director and the hospital administrator petitioned the Hennepin County Board of Commissioners to allow the hospital to take this issue to court. After receiving permission, the hospital took a two-step legal procedure: first they asked for the appointment of an independent conservator to decide whether the respirator provided any benefit to the patient and secondly, if the conservator agreed that the treatment provided no benefit, whether the hospital could stop prescribing it.⁷ At this point Mr. Oliver Wanglie (Mrs. Wanglie's husband, a lawyer) cross filed petitioning to be appointed the conservator. In July 1991, the court ruled that Mr. Wanglie be appointed as conservator because (as her husband) he was the best person to represent Mrs. Wanglie's interests. As a result, the second part of the two-step procedure did not occur. Mrs. Wanglie died shortly thereafter and the family stated that she had received excellent care.

⁷Miles, S., "Informed Demand for "Non-Beneficial" Treatment," pp. 512-515.

Comparison of *Quinlan* and *Wanglie*

The *Quinlan* case is a widely cited autonomy case and *Wanglie* is the paradigm medical futility case. These two cases help reveal the current dilemma concerning the idea of medical futility and the ambiguous role of the principle of respect for patient autonomy. In both *Quinlan* and *Wanglie* the patient was female, in P.V.S. and in both cases the families were actively involved in the treatment process. Despite the fact that both women had the same diagnosis and prognosis the professional recommendation about the proper course of treatment was not only different but contradictory. In *Quinlan* the doctors insisted on continuing treatment despite the family's wishes, whereas, in *Wanglie* the doctors insisted on stopping treatment despite the family's wishes. One important distinction between the two, however, is their age which often modulates individual's responses to situations and demonstrates that individual values play a large role in the decision-making process.

These two cases contain many distinguishing features. However, I suggest that the most important aspect concerns the seemingly lost capacity of doctors to determine what is best for their patients. In the case of Karen Quinlan the dispute was about who knows what was in Karen's best interest, the doctor or the patient (and/or family). In addition to this question, *Wanglie* suggested that there was the further question of medical knowledge and the question of who was the most proper decision maker in this situation. There are different positions that we may adopt in order to approach this situation. One is to focus on the disagreement between the physician and the patient or the family. This approach has been

undertaken by the majority of authors who have contributed to the futility debate. Another is to take a step back, and ask ourselves “what is at stake here?”. I intend to focus on the second approach, but first it is necessary to introduce the standard definitions of futility and the different arguments that constitute this debate.

Different Conceptions of Futility

Ms. Quinlan's case is a standard example of a patient (or surrogate) exercising autonomy. The issue at stake concerned the family forcing doctors to stop providing treatment that the professionals believed was in her best interest, both sides of the issue revolved around who had particular knowledge concerning the patient's best interests. However, Mrs. Wanglie's case is an example of the moral conflict inherent in the medical futility debate.⁸ The Hospital staff sincerely believed that continued treatment was futile; whereas Mrs. Wanglie's family disagreed with equal sincerity. In this dilemma, the medical facts were not in dispute. Ronald Cranford on behalf of the *Hastings Center* reports:

The principal parties do not dispute most of the medical facts. The family accepts the diagnosis of persistent vegetative state and respirator

⁸Most futility cases are in relation to patients in a persistent vegetative state or relate to cases involving cardiopulmonary resuscitation and do-not-resuscitate orders. However, it also applies in situations where organ-replacement technology is used. There is a procedure called extracorporeal membrane oxygenation which can replace heart and lung function, for up to several weeks, in any patient. Caregivers do not offer this therapy to terminally ill patients because of the belief that it would be futile. This decision is generally made unilaterally, without any input from the patient. Truog, R., Brett, A., and Frader, J., “The Problem with Futility,” *New England Journal of Medicine*, Volume 326, (1992) Pages 1560-1564.

dependence.⁹

The disagreement, between the professionals and the family, was primarily about whether the family was entitled to demand treatment that the health care providers believed to be useless and not worth pursuing. It is as if the two parties wanted to claim some type of special knowledge that justified them in making their decision. The Wanglie family had intimate personal knowledge of Mrs. Wanglie, whereas the health care professionals had a very specialized knowledge which they thought justified them in overriding the family's wishes.

In *Quinlan*, the disagreement is limited to deciding whether it is more appropriate for the physicians or patient (and/or family) to decide Ms. Quinlan's best interests. In fact, the matter was resolved when the court was presented with acceptable proof of Karen's definition of her own best interests. However, in the *Wanglie* case the debate is a little different. First, although the medical facts were not in dispute there was debate over medical knowledge. The Wanglie family insisted that the professionals provide treatment that in their professional opinion was futile. And they also disagreed over whether it was in Mrs. Wanglie's best interest to be kept alive in P.V.S.

The confusion, exemplified by the *Wanglie* case, has recently been explored by numerous commentators in the literature. Lawrence Schneiderman and Nancy Jecker have done considerable work on the problem of medical futility and have attempted to sidestep some of the term's ambiguities. Very briefly, some of the ambiguities associated with the term futility are the following: are these medical decisions or value judgments? at what point is

⁹Cranford, R., "Helga Wanglie's Ventilator," *Hastings Center Report*, (July-August 1991), pp. 23-24.

a person's quality of life so poor that continued treatment should be considered futile? at what point are the chances of success so remote that continued treatment should be considered futile? who gets to decide these thresholds, the patient or the doctor? Ultimately, it will come down to deciding who has the requisite knowledge to make these claims; is it the patient (or family) with intimate personal knowledge or the professional with specialized knowledge?

Concerning futility, Schneiderman and Jecker have proposed a distinction between quantitative and qualitative determinations of futility, offering specific thresholds for both.¹⁰

First concerning the *quantitative* sense of futility they say:

Since we can never say never, can we agree that if a treatment has not worked in the last 100 cases, it would be “reasonable” to conclude that it is futile?¹¹

Schneiderman and Jecker then suggest the following as a guideline for determining *qualitative* futility:

If a patient lacks the capacity to appreciate the benefit of a treatment, or if the treatment fails to release a patient from total dependence on intensive medical care, that treatment should be regarded as futile.¹²

According to these definitions, if a treatment has not worked in the last 100 cases or if the

¹⁰There is evidence in the literature that most people are accepting Schneiderman's and Jecker's specific definitions. Most commentators agree that at some point the probabilities are so remote or the quality of life is so poor, that treatment should not be offered. Exactly where this threshold is and how it is to be determined are matters that call for further discussion. However, I consider Schneiderman's and Jecker's positions to be the standard positions against which the others will be examined.

¹¹Schneiderman, L., and Jecker, N., *Wrong Medicine: Doctors, Patients, and Futile Treatment*, (Baltimore and London: The John Hopkins University Press, 1995) p. 15.

¹²*Ibid.*, p. 17.

patient cannot appreciate the benefit of treatment and/or is permanently dependent on intensive medical care, further treatment should be considered either quantitatively or qualitatively futile.

Of course, there are problems with these definitions and not everyone would accept them. For instance, with the quantitative definition some patients and/or practitioners may not want to wait until something has failed 100 times before it is considered futile and others may wish to pursue even more remote chances of success because 100 failures may not be sufficient evidence to prove, for some patients, that treatment is futile. Schneiderman and Jecker acknowledge this concern and state:

Although we have presented a specific proposal, we recognize that people may disagree about exactly where the threshold for futility should lie. For example, some may think that waiting for 100 failures before acknowledging a treatment's futility sets the threshold too low. However, the important consideration is that all would probably agree with our more general claim that *at some point* the likelihood of medical success is so poor that attempting to achieve it is futile.¹³

Likewise, with the definition of qualitative futility, it is not clear why treating a patient who can appreciate the benefit of treatment, but is at the same time permanently dependent upon intensive care, should be considered futile. In anticipation of this type of concern Schneiderman and Jecker appeal to the ends of medicine, they quote Plato's The Republic:

For those whose lives were always in a state of inner sickness Asclepias [a mythical demigod-physician] did not attempt to prescribe a regimen [...] to make their life a prolonged misery. [And] a life of preoccupation with illness

¹³Schneiderman, L., and Jecker, N., *Wrong Medicine: Doctors, Patients, and Futile Treatment*, p. 15.

and neglect of work isn't worth living.¹⁴

Schneiderman and Jecker apply this type of reasoning to their definition of qualitative futility and suggest that if someone is overcome by his or her infirmity and is confined to intensive care, treatment should be considered futile because medicine is not supposed to attempt to keep people enslaved to modern technology in the intensive care unit.¹⁵ They say:

The ends of medicine lie not with mere biological survival nor with the patient imprisoned within machines and tubes. At the very least, the ends of medicine require providing the patient with the capacity to participate in the human community. And though this level of participation can be minimal, common sense would dictate that it does not refer to insensate bodies or patients irrevocably immersed in a hospital's life-support machinery.¹⁶

Once again Schneiderman and Jecker acknowledge that there are potential problems with their specific definitions of qualitative futility:

Again, not everyone may agree with the threshold we have chosen for qualitative futility. For instance, some may urge that a life-saving treatment be regarded as futile if the patient will not survive to hospital discharge. Others may accept our more conservative view that life-saving measures on behalf of a patient who is confined to a hospital bed are not necessarily futile. Despite these specific disagreements, we believe that everyone can agree with our more general idea that *at some point* the quality of medical outcome may

¹⁴Schneiderman, L., and Jecker, N., *Wrong Medicine: Doctors, Patients, and Futile Treatment*, p. 16. Plato., *Republic bk. 3*, trans. E. Hamilton and H. Cairns (Princeton: Princeton University Press, 1980).

¹⁵Schneiderman and Jecker do not explicitly define intensive care but they imply that it has to do with dependence on technology. "Intensive care units (ICUs) were developed in the late 1960s to provide a temporary high-technology environment to enable teams of medical providers to rescue patients with acute, serious, life-threatening disease. Patients were expected either to survive and be transferred out of the unit or to die." Schneiderman, L., and Jecker, N., *Wrong Medicine: Doctors, Patients, and Futile Treatment* (Baltimore and London: The John Hopkins University Press, 1995) p. 44.

¹⁶Schneiderman, L., and Jecker, N., *Wrong Medicine: Doctors, Patients, and Futile Treatment*, p. 18.

become so poor that it is futile.¹⁷

One could very easily disagree with the specific thresholds for futility that Schneiderman and Jecker suggest; in fact, Schneiderman himself admits that they are not objective or value-free definitions, but rather that they seek reasonable consensus where absolute certainty is impossible and therapeutic benefit is the goal.¹⁸ However, the foundation of their position is that “at some point the likelihood of medical success is so poor that attempting to achieve it is futile,” (quantitative futility) and “at some point the quality of medical outcome may become so poor that it is futile”¹⁹ (qualitative futility). Schneiderman and Jecker think that everyone is compelled to agree to these foundational claims, although the specific threshold may vary.

The implications of their view are that the physician, because of his or her particular knowledge, skills and experience, could unilaterally impose a futility label and this would justify him or her in not offering the treatment to the patient. Schneiderman says:

“If we can agree to call this treatment futile then the ordinary duty of the physician does not require offering it.”²⁰

In addition to not offering a course of treatment that is considered quantitatively or qualitatively futile, the physician may also withdraw treatment once it has been determined

¹⁷ *Ibid.*, p. 18.

¹⁸ Schneiderman, L., “The Futility Debate: Effective versus Beneficial Intervention,” *Journal of the American Geriatrics Society*, Volume 42, Number 8, (1994), pp. 883-886.

¹⁹ Schneiderman, L., and Jecker, N., *Wrong Medicine: Doctors, Patients, and Futile Treatment*, pp. 15-18.

²⁰ Schneiderman, L., “The Futility Debate: Effective versus Beneficial Intervention,” pp. 883-886.

that the present course of treatment is futile. Both the withholding and the withdrawing of treatment would be done with or without the patient's consent, because a futility label, on this model, would justify professional unilateral decision-making.

Withholding and Withdrawing Medical Treatment

It is important at this point to discuss, very briefly, the concepts of withholding and withdrawing treatment. Philosophers in general, and most medical ethicists in particular, argue that there is no moral difference between withholding and withdrawing treatment while one is an act and the other is an omission the same arguments can be applied to justify both, in the appropriate circumstances.

Withholding and withdrawing treatment were previously known as "passive euthanasia;" but this term has become very pejorative and most commentators have abandoned it. The point is, however, that there appears to be an intuitive difference between withholding treatment and withdrawing it after it has started. Although most argue that there is no moral difference between the two, a pragmatic position is to attribute a difference to not initiating treatment, as opposed to stopping it (or as some would call it "pulling the plug").

Theorists can debate endlessly whether this act/omission distinction is morally relevant, but it probably matters substantially more to the average patient and his or her family. Dr. Somerville, when she appeared before the Senate Committee on Euthanasia and Assisted Suicide, expressed this concern in the following:

There is also an issue about there being any difference between withholding and withdrawing life-sustaining treatment. Ethically and legally there is not,

provided in either case the act is justified. Again, to some extent, whether it is justified is a value judgment. However---and I think we need to acknowledge this---withdrawing treatment can feel different from withholding treatment for the health care professionals involved.²¹

It could be consistently argued that withdrawing treatment probably “feels” different from withholding treatment for the patient and/or family involved also.

This confusion between the act/omission distinction, can be set in context with education and communication. A particularly helpful way to understand the similarity between the two is to note the consequences of the position that withholding treatment is more acceptable (or morally different) than stopping it after it has been determined that it does not work. The President’s Commission states this as follows:

If a trial therapy makes clear that it is not helpful to this patient, this is actual evidence (rather than surmise) to support stopping because therapeutic benefit that earlier was a possibility has been found clearly unobtainable.²²

If the patient (and/or family) trusts the physician, it is possible to agree to a trial therapy with the understanding that it is occasionally better to try a procedure and stop it once it is determined that the procedure is not working than to refuse to implement it because withdrawing would be too difficult. The result of refusing to stop treatment after it has been shown not to work would be a hesitancy to initially implement uncertain therapies, which would deny patients potentially beneficial treatments because of a fear that once treatment

²¹Senate of Canada *Of Life and Death: Report of the Special Senate Committee on Euthanasia and Assisted Suicide* Published under the authority of the Senate of Canada (June 1995), p. 44.

²²*President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research. Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions*, p. 60.

was begun it could not be stopped. This type of confusion is something that can be avoided if everyone, health care professionals and patients and/or families is on the same wave length through education and communication.

This complicated issue cannot be adequately addressed in such a brief discussion. However, there is a wealth of literature on this topic which suggests that for all intents and purposes the distinction between the two is not morally relevant. This is also the position of the Special Senate Committee on Euthanasia and Assisted suicide, along with the Canadian Medical Association. Although this is a very important topic, a protracted discussion of it would detract from the main point of this thesis. Therefore, based on the general consensus in the literature and the brief discussion above, no morally relevant distinction between the two---withholding and withdrawing treatment---will be argued for in this thesis.

Futility and Withdrawing Treatment Without Consent

The position supported by the American Thoracic Society on life-sustaining therapy allows health care professionals to withdraw or withhold futile treatments without the patient's consent and in some instances against the patient's (and/or families) wishes. The Society states that life support

can be limited without the consent of [the] patient or surrogate when the intervention is judged to be futile[...]²³

This is also the position that was supported in the 1995 *Gilgunn V. Massachusetts*

²³American Thoracic Society., "Withholding and Withdrawing Life-Sustaining Therapy," *Annals of Internal Medicine*, Volume 115, Number 6 (1991), pp. 478-485.

*General Hospital*²⁴ case. In 1989, Mrs. Catherine Gilgunn, then 71 years' old, fell and broke her left hip and two weeks later was admitted into the Massachusetts General Hospital on June 7, 1989.²⁵ Prior to this incident Mrs. Gilgunn was already in very poor health. She suffered from diabetes, heart disease, chronic urinary tract infections and a few years earlier she was diagnosed with Parkinson's disease. In 1988 she suffered a stroke from which she did not fully recover and she had previously undergone a mastectomy for breast cancer. On June 16, 1989, Mrs. Gilgunn suffered two grand mal seizures and experienced repeated seizures until June 29, which resulted in brain damage, coma and respirator dependence.

Mrs. Gilgunn's daughter (Joan, age 31) was appointed as surrogate decision-maker. Joan made it very clear that her mother wanted everything done that was medically possible. Therefore, out of respect for her mother's wishes she would not consent to the withdrawal of care or to a do-not-resuscitate order. Regardless of Joan's (perhaps even Mrs. Gilgunn's) refusal to consent, the attending physician, Dr. Dec, entered a do-not-resuscitate order on Mrs. Gilgunn's chart and began to wean her from mechanical ventilation. Three days after the weaning process began, Mrs. Catherine Gilgunn's breathing stopped and she died on August 10, 1989. When this case went to court the jury found that the care provided to Mrs. Gilgunn was indeed futile and that the physician did not need the surrogate decision maker's consent to stop providing/withdraw futile treatment.²⁶

²⁴Superior. Ct. Civ. Action No. 92-4820, Suffolk Co., Mass., *verdict*, (21 April 1995).

²⁵Capron, A., "Abandoning a Waning Life," *Hastings Center Report*, (July-August 1995), pp. 24-26.

²⁶Capron, A., "Abandoning a Waning Life," pp. 24-26.

The Gilgunn case and the position of the American Thoracic Society demonstrate one of the central issues of the futility debate. This issue centres on how to resolve the conflict that arises when the doctor and patient (or surrogate) disagree about these important decisions (i.e. who has a particular kind of knowledge.) As we have seen through the comparison of *Quinlan* and *Wanglie*, professionals may provide contrary recommendations in these complicated situations. Likewise, some patients (or their surrogates) may simply deny the reality of the situation and make unreasonable demands from health care professionals.

This dilemma has been thoroughly debated in the literature on this subject. Some commentators have argued that physicians are not qualified to make these determinations unilaterally and that they are never justified in refusing to treat patients, on the grounds of a unilaterally determined futility judgment. Whereas, others have argued that health care professionals should be entitled to make futility determinations, as a part of practising responsible medicine. These two positions will be explored next.

Arguments Against Professional Unilateral Decision-Making Based on a Futility Determination

Doctors have highly specialized knowledge, technical expertise, and clinical experience that assist them in practising the art and science of medicine competently. These characteristics are the primary reasons that one seeks the assistance of a practising physician. However, some commentators argue that specialized knowledge, technical competence, and clinical experience do not make the professional an expert at determining quality of life issues

(qualitative futility) or at determining whether the probabilities of success are too remote to be worth pursuing (quantitative futility). Felicia Ackerman uses the following analogy to make this point:

It is as presumptuous and *ethically* inappropriate for doctors to suppose that their professional expertise qualifies them to know what kind of life is worth prolonging as it would be for meteorologists to suppose their professional expertise qualifies them to know what kind of destination is worth a long drive in the rain.²⁷

Ackerman's point in this quotation is that despite the professional's highly specialized knowledge concerning medical matters, he or she simply does not have the appropriate knowledge to make these types of decisions unilaterally.

In addition to the fact that specialized knowledge, clinical expertise, and experience do not necessarily qualify professionals to make quality of life decisions or to determine the worth of pursuing a long shot, commentators argue that there is an implied promise which accompanies medical licensure that requires clinicians to use treatments to attempt to extend life when the patient or surrogate requests it.²⁸ For instance, a physician who holds unusual beliefs about race, gender or religion, is still required to provide treatment to patients whom he or she finds it offensive to treat. Although the physician holds these beliefs sincerely and it would be against his or her integrity to treat these patients, it does not allow him or her to refuse to treat them because he or she has implicitly promised to treat these patients, by accepting a license to practice medicine. Robert Veatch explains:

²⁷Ackerman, F., "The Significance of a Wish," *Hastings Center Report*, (July-August 1991), pp. 27-29.

²⁸Veatch, R., and Spicer, C., "Futile Care: Physicians Should Not Be Allowed to Refuse to Treat," *Health Progress*, Volume 74, Number 10 (December 1993), pp. 22-27.

The medical profession as a whole has, by its long-standing practice, established the expectation that patients who want life-prolonging care will receive it. Even in Helga Wanglie's case, clinicians clearly opposed to the care continued to provide it until she died. One might argue that the profession has implicitly promised patients that life-prolonging care will be provided, even if it violates the personal religious and philosophical judgments of the provider regarding its usefulness.²⁹

Veatch further argues, that from this implied promise emerges a notion of justice, which he believes provides the patient with a limited entitlement right (positive right). Veatch puts restrictions on this entitlement right, such as an ongoing doctor-patient relationship and proper funding for the procedure; however, his central point is that in certain respects the patient is vulnerable and should be entitled to life-prolonging care if he or she wants it. He says:

The principle of justice requires that benefits be distributed more equally or to improve the lot of the worst off. Arguably, some patients who are demanding care deemed futile are among the worst off. If so, they would have a limited entitlement right that should be reflected in the promises society extracts from providers as a condition of monopoly licensure.³⁰

Any discussion of the "implicit promise of treatment" must be examined within the larger structure of health-care and economics, in both the United States and Canada. In the United States, the implicit (and indeed explicit) promise is that the patient receives the treatment that he or she has paid for through insurance. As a result, if the person has not paid for certain treatments he or she will not receive them, futile or not. Likewise, if they are paid for, the person will receive them. However, it is not clear whether futile treatments fall within

²⁹Veatch, R., "Why Physicians Cannot Determine If Care Is Futile," *Journal of the American Geriatrics Society*, Volume 28 Number 8, (1994), pp. 871-874.

³⁰Veatch, R., "Why Physicians Cannot Determine If Care Is Futile," pp.871-874.

this category as the case of Helga Wanglie demonstrates. Regardless, the implicit promise of treatment depends entirely upon what insurance the person bought. Of course, things are very different in Canada where people have public insurance. In a system with public insurance, the implicit promise is that the patient receives what the state has defined as insured services. There is a mechanism which decides which services (including drugs) are insured — a decision which is made by the government, not individual doctors — and every Canadian citizen is entitled to access those insured services. Whether the individual receives futile treatments depends on whether they are or are not included in the list of insured services. Therefore, what patients are promised is determined either by their private insurance (in the U.S.) or by the government's list of insured services (in Canada).

There are two important issues here: first, Veatch may concede this point but argue that nevertheless, there are occasions when the provider refuses to provide care that is paid for on the grounds of futility. He says:

Still, they [health care professionals] may have other reasons for wanting to remove themselves from providing such care. They often claim that participation in delivery of such services violates their integrity as clinicians.³¹

Secondly, Veatch provides a list of six conditions that must be met before this duty will prevail; namely the duty to provide patients who are deemed the worst off with treatment that they desire regardless of whether the professional believes that treatment is futile or not.

- First, the care would have to be equitably funded. We have seen that that condition can be met and that it is not the clinician's obligation to limit care on that basis.
- Second, the principle of justice itself requires that the duty to provide such care would be subordinated to the claims of other patients who are even worse off. Still in cases

³¹Veatch, R., "Why Physicians Cannot Determine If Care Is Futile," pp. 871-874.

in which the clinician acknowledges that provider time and talent are not a limited resource, a promise to provide care should be honored.

- Third, a promise to provide care deemed futile should be limited to cases involving ongoing patient-physician relationships.
- Fourth, society should limit the duty to cases in which the clinician is competent to deliver the desired care.
- Fifth, it should limit it to patients for whom the clinician cannot find a competent colleague to whom to transfer the case.
- Sixth, and most important, it should limit the promise to interventions that I will call “fundamental.” Some desires of patients or surrogates are clearly frivolous or terribly implausible. The patient who wants a leg amputated to spite a lover would be an example.³²

These requirements reveal that the cases Veatch is concerned with are situations in which the patient has insurance or the government has approved the particular form of treatment, but the physician has decided that continued treatment is futile and thus desires to withhold or withdraw it unilaterally. This was the situation in Mrs. Wanglie’s case. She had adequate funding but the professional did not want to provide the treatment regardless.

To this point I have presented three different positions that suggest that professionals should not be entitled to make these futility determinations unilaterally: (1) professionals are not uniquely qualified to make these decisions because they do not possess any special knowledge by virtue of having a medical degree (2) there is an implied promise (of treatment) that accompanies medical licensure, and (3) the principle of justice suggests that people who are the worst off have limited entitlement to assistance. However, the essence of these positions can be summed up in the following:

³²Veatch, R., “Why Physicians Cannot Determine If Care Is Futile,” pp. 871-874.

When the chance of success is low, but the alternative to treatment is death, and the patient [or surrogate] desires therapy, the presumption should be in favour of treatment.³³

This argument implies that if the professional made a futility determination unilaterally, despite the patient's claims to the contrary, he or she would be saying that it is in the patient's best interest and the patient is better off without treatment, regardless of what the patient thinks or wants, and despite the fact that the alternative is death. The claim that the professional can unilaterally decide whether treatment is beneficial and whether it is in the patient's best interest to provide, is a form of paternalism which autonomy advocates like Veatch, Spicer, and Ackerman simply cannot accept. Veatch says:

A review of the key futility cases — Wanglie, Baby L, and most others — reveals general agreement between the clinician and surrogate that an intervention will have an effect. My first claim is that a clinician has no expertise in deciding whether those effects are beneficial.³⁴

The fear is that the physician has no unique qualifications to make these types of decisions, i.e., he or she does not have the appropriate knowledge. As has been argued by Veatch, Ackerman and others, nothing in medical school trains a physician to know whether the effect of treatment is beneficial to the patient because this will in large part depend upon the patient's subjective preferences. In support of this position Youngner says:

[...] all judgments that lead to the conclusion that a treatment is of no benefit involve value judgments.³⁵

³³Lantos, J., et al., "The Illusion of Futility in Clinical Practice," *The American Journal of Medicine*, Volume 87, (July 1989), pp. 81-84.

³⁴Veatch, R., "Why Physicians Cannot Determine If Care Is Futile" pp. 871-874.

³⁵Youngner, S., "Who Defines Futility?" *Journal of the American Medical Association*, Volume 260, (1988), pp. 2094-2095.

Advocates of autonomy want to argue that if it is value judgments that rule these decisions, then it should be the patient's values that dominate the decision-making process and not the physician's. At the very least, the patient's values should be considered and the patient should not be subjected to the professional's unilateral value judgment.

Arguments for Unilateral Professional Decision-Making

Most commentators concede that technical expertise and clinical experience do not uniquely qualify physicians to decide quality of life issues, or to decide whether a long shot is worth pursuing. However, clinicians do argue that technical expertise and clinical experience have a certain relevance that can assist in making these important decisions.

Professionals accumulate valuable experience as they work in the clinical setting and despite the fact that this experience does not provide the professional with the last word concerning value judgments, one is not justified in simply dismissing it. Consider for example the following, which emphasizes the often unknown invasiveness of clinical treatment:

Patients and surrogates experience the progression of a fatal illness only once, and it may be difficult to envision the concrete consequences of a treatment intervention. For example, they may not fully apprehend the violent nature of cardiopulmonary resuscitation performed on a fragile elderly patient, or adequately visualize the atrophy of muscle, joints and skin that befalls a chronically immobile stroke patient sustained by tube feedings.³⁶

The idea of professional integrity has emerged as a position that intends to counter patient's demands for treatment that the professional believes will result in an unacceptable

³⁶Ackerman, T., "Futility Judgments and Therapeutic Conversation," *The Journal of the American Geriatrics Society*, Volume 42 Number 8 (1994), pp. 902-903.

quality of life or that are not worth pursuing. There are two general requirements attached to this idea:

- (1)Physicians ought not fraudulently misrepresent their knowledge or skills of medical practice.
- (2)Physicians ought not administer treatments that cause harm disproportionate to any foreseeable benefit.³⁷

The disagreement about whether treatment is futile or not is sparked because it is not always clear what constitutes a benefit to the patient. Despite incredibly sophisticated technology, sometimes comfort care is the most the professional believes that he or she can offer. The idea of professional integrity comes in because this limitation is something that physicians are ethically obligated to admit. In fact, a physician who offers an intervention that, in his or her opinion, will not benefit the patient, has acted unethically, by deceiving the patient and compromising the professional standards of medicine. Raising false hope is completely unacceptable according to commentators like Nancy Jecker and Lawrence Schneiderman, who state their position as follows:

In short, physicians who prescribe treatments that they are reasonably confident will not improve the patient's condition break trust with patients and denigrate the practice of medicine. Their conduct allies medicine with quackery and physicians with charlatans.³⁸

In addition to the mixed message that is sent by offering futile treatments, the iatrogenic harms that accompany most treatments often demand that the intervention not be

³⁷Brody, H., "The Physician's Role in Determining Futility," *The Journal of the American Geriatrics Society*, Volume 42, Number 8, (1994), pp. 875-878.

³⁸Jecker, N., and Schneiderman, L., "Medical Futility: The Duty Not To Treat," *Cambridge Quarterly of Healthcare Ethics* Volume 2, (1993), pp. 151-159.

performed if it is considered futile. Consider for example the inherent risk of harm in cardiopulmonary resuscitation: ribs can be broken, the trachea damaged, and often the brain never completely recovers from oxygen deprivation.³⁹ These potential harms have little effect on the overall judgment in favour of treatment when the possibilities for benefit are reasonable, but they dominate the decision making process when the potential for benefit is virtually nonexistent, or when it is the procedure itself that can be fatal.⁴⁰

Schneiderman and Jecker also argue that a professional standard for determining futility is required. They believe that if there is no professional standard, the ambiguity associated with the term will provide the opportunity for arbitrariness and abuse. They state the position as follows:

...[I]n the absence of a general professional ethic affirming the scope and limits of physicians' obligations, the meaning and ethical implications of futility are vulnerable to abuse.⁴¹

The fear is that without established criteria for the necessary and sufficient conditions of "futility" other factors could be used to guide the decision-making process. If doctors were free to determine when a treatment is futile themselves, it could mean whatever they want it to mean. By using the undefined term 'futility', one could really mean that the treatment is too expensive, or the patient is too difficult to have to explain these details to, or that the

³⁹Jecker, N., and Schneiderman, L., "Medical Futility: The Duty Not To Treat," *Cambridge Quarterly of Healthcare Ethics*, Volume 2, (1993), pp. 151-159.

⁴⁰Tomlinson, T., and Brody, H., "Futility and the Ethics of Resuscitation," *The Journal of the American Medical Association*, Volume 264, Number 10, (1990), pp. 1276-1280.

⁴¹Schneiderman, L., and Jecker, N., *Wrong Medicine: Doctors, Patients, and Futile Treatment*, p. 104.

patient is simply ungrateful and the physician could use his or her talents better elsewhere.⁴²

Analysis of Decision-Making Power in the Clinical Setting

The arguments for patient-based decision-making revolve around the claim that the physician cannot deny treatment that the patient believes has value and is beneficial simply because the physician believes otherwise. This approaches the situation in the Wanglie case. The health care providers suggested that Mrs. Wanglie was not benefiting from treatment and that being alive in PVS, dependent on a respirator, is not worthwhile. However, if Mrs. Wanglie's wishes were more certain, perhaps the health care providers would not have been so adamant. For instance, there was a point when Mrs. Wanglie was conscious, but at the same time respirator dependent. Attempts to address her treatment preferences yielded inconclusive results and her wishes were not adequately clarified. Perhaps, if the topic had been discussed with her and her family more thoroughly at this point, the situation might not have been so tragic.

The argument that supports unilateral professional decision-making concerning futility rests on the premise that there is a need for a professional standard to determine futility, because without a uniform standard there is no guarantee about the motivation for labelling a particular course of treatment futile, or for the appropriate threshold of a futility determination. One of the consequences of this is a breakdown in the level of trust between the doctor and the patient. If we look at the Wanglie case, one of the central issues is the lack

⁴² *Ibid.*, p. 104.

of trust between the health care professionals and the Wanglie family. The Wanglie family accused the doctors of wanting to play God. However, if the professionals had a standard to appeal to that was established prior to Mrs. Wanglie's tragedy, perhaps the situation would not have escalated the way it did.

Both of these positions are very convincing. The disagreement inherent in the "futility" debate is extensive, and the intention of these positions is to either resolve or avoid the conflict, by assigning decision-making power to either the physician or the patient. It is very difficult not to take sides in this spirited debate; however, one must not. By taking sides, the problem of futility is framed in terms of a power struggle between the physician and patient or between professional paternalism and patient autonomy. However, I think that a more fundamental problem is the lack of trust between the patient and physician.

This lack of trust is twofold: (1) the patient (and/or family) do not trust the health care professionals. This is clearly the situation in the *Wanglie* case where the family accuse the professionals of wanting to play God. And (2) there is also a distrust by the professional of the patient (and/or family). This is also evidenced through the *Wanglie* case when the hospital petitioned the court to appoint someone other than a family member as an "independent" conservator. Arthur Caplan explains this position:

The problem that faces those who put their hope in medical futility as a way to rationalize the provision of care is not the lack of consensus about a definition but the absence of trust between physician and patient [...]⁴³

Caplan goes on to say:

⁴³Caplan, A., "Odds and Ends: Trust and the Debate over Medical Futility," *Annals of Internal Medicine*, Volume 125, Number 8 (October, 1996), pp. 688-689.

Without trust, outcome-based medicine is doomed. If a patient or a family is to trust the physician's pronouncement that mechanical ventilation should not be continued beyond a fixed number of days after bone marrow transplantation or that a child born with anencephaly will not recover no matter what is done, they must trust the physician. Numbers alone, even grim ones derived from thousands of cases and years of experience, will not suffice.⁴⁴

It is this lack of trust that the power-struggle stimulates by attacking the communication process and advocating silence. The professional desire to make these decisions unilaterally and the patient desire to insist on certain forms of treatment attempt to avoid working out these complicated disagreements through dialogue and communication by resorting to power or the ability to force the other side to comply. Terrence Ackerman explains:

Using this paradigm, we are compelled to assign unilateral decision-making authority to the physician, the patient or surrogate, or an appropriate review body. However, physicians and patients or surrogates almost always agree about the futility of a treatment if there has been careful and complete conversation about treatment goals that are both achievable and desirable. When there is initial disagreement, it can usually be resolved if therapeutic goals are reviewed, factual misunderstandings are corrected, affective constraints are ameliorated, or the consequences of treatment interventions fully appreciated. Opting for unilateral decision-making based on atypical cases of irresolvable conflict dismisses the pattern of conjoint deliberation that produces well considered and shared judgments of futility in most clinical circumstances. Thus, we should insist that judgments of futility issue from deliberative dialogue within the therapeutic relationship.⁴⁵

One of the most fundamental concerns of the futility debate, whether acknowledged or not, is with the absence of trust between the patient and the physician. One possible way

⁴⁴ *Ibid.*, pp. 688-689.

⁴⁵ Ackerman, T., "Futility Judgments and Therapeutic Conversation," *Journal of the American Geriatrics Society*, Volume 42, Number 8, (1994), pp. 902-903.

to create trust is to articulate a clear picture of the legitimate roles of the doctor and patient in this unique relationship. The role of the patient has been largely developed through the massive literature on patient autonomy; but as we have seen, this autonomous role is not clear concerning “futility.” In addition, the legitimate role of the physician and the proper domain of professional authority is very ambiguous. Therefore, I suggest that simply devising arguments to support patient or professional decision-making power misses the more fundamental issue of establishing trust in this complicated clinical relationship.

Clearly it is important to deny futile and potentially harmful care, however, it is equally important to minimize or eliminate patient requests for these futile and potentially harmful procedures by getting everyone (doctors, patients and/or families) on the same wavelength.⁴⁶ My intention, therefore, is to leave the boundaries of the futility debate and approach it from a new perspective, namely, the angle of patient and professional authority. I will develop a normative conception of professional authority that is consistent with patient autonomy and claim that professional authority is not only compatible with patient authority but show that patient authority cannot exist without acknowledging the unique role of professional authority in the doctor-patient relationship. Along with professional authority’s foundational role in the development of trust, it will be argued that a properly conceived conception of professional authority is the basis for trust. Once these roles are properly articulated, it will be shown that doctors should not be seen in opposition to patients but that the true enemy is blind obedience to a principle (autonomy) and disregarding the essential role of the

⁴⁶Youngner, S., “Applying Futility: Saying No Is Not Enough,” *Journal of the American Geriatrics Society*, Volume 42, Number 8, (1994), pp. 887-889.

physician in this relationship. I intend to show that both patient and professional authority are interconnected in such an intimate way that they cannot be legitimately exercised if they are estranged from each other, as the futility debate would have through unilateral decision making.

Chapter Three

The Idea of Authority

The doctor-patient relationship has changed drastically over the past 25 years. It has evolved from a relationship that was dominated by professional paternalism, into one that is governed by the principle of respect for patient autonomy. Paternalism consists of the physician unilaterally deciding what is in the best interest of the patient.¹ The aim of the paternalistic physician is to ensure that the patient receives the medical attention that would promote his or her best interest (according to the physician's conception of the patient's best interests). On this model the physician would utilize his or her technical skills to provide an accurate diagnosis and identify the medically indicated treatment (without regard for the patient's subjective preferences). The paternalistic physician would then present the patient with selected information that would facilitate the gaining of his or her consent to the intervention.²

The principle of respect for patient autonomy successfully challenged this model and

¹Emanuel, E., and Emanuel, L., "Four Models of the Physician-Patient Relationship," *Journal of the American Medical Association*, Volume 267, Number 16, (April 1992), pp. 2221-2226.

²It is important to realize that on the paternalistic model, the patient's consent is not an informed consent. The physician presents only that information which he or she believes will facilitate gaining the patient's consent.

professional paternalism is currently in disrepute. Patient autonomy is championed by the doctrine of informed consent, which necessitates that the patient be sufficiently informed of the relevant risks, benefits and alternatives, before his or her consent is considered valid.³ As a result of this press for patient autonomy, many believe that the actual medical decision-making process has been hindered by placing too much decision-making power in the hands of patients and/or families, in the doctor-patient relationship. Koch, Meyers and Sandroni state this phenomenon as follows:

During the 1980's the balance of power in medical decision-making has swung from the physician towards the patient and family, in the name of patient autonomy.⁴

The history of bioethics is replete with examples and case studies that reveal the importance of respect for the principle of patient autonomy and the indispensable function that respect for this principle serves is readily acknowledged by most commentators.⁵ However, the medical futility debate has created substantial confusion about the suitability of

³*Reibl v Hughes*, p. 4.

⁴Koch, K., Meyers, B., and Sandroni, S., "Analysis of Power in Medical Decision-Making: An Argument for Physician Autonomy," *Journal of Law, Medicine & Health* Volume 20, Number 4, (1992), p. 326.

⁵For example there is the Jewish Chronic Disease Hospital case where experimenters wanted to test the body's reaction to the injection of foreign cells. They proceeded to inject cancer cells into patients to see how the body would react to these foreign cells. This was done without the patient's consent. ["The Jewish Chronic Disease Hospital Case" in Katz, J, *Experimentation With Human Beings: The Authority of the Investigator, Subject, Professions, and State in the Human Experimentation Process*, (New York, Russell Sage Foundation, 1993.)] There is also the previously discussed case of Walter Halushka who was a student who participated in an experiment for \$50. He was told that the experiment was innocuous but he suffered a cardiac arrest and had to be resuscitated by open heart message. [*Halushka v University of Saskatchewan et al.* 52 W.W.R. 608 (Sask. CA. 1965) p. 690.]

either professional paternalism or the principle of respect for patient autonomy and has revealed the inadequacy of unilateral decision-making by either the patient or physician. Medical interventions, which are not concerned with the futility debate, furnish the principle of respect for autonomy a very robust position. Without labeling a procedure futile it would be very rare that a professional would not elicit the informed consent of a patient. In fact, it appears that the current emphasis using a limited interpretation of this principle has created confusion between the ideas of independent choice and respect for the principle of autonomy.

Quill and Brody explain that there is an existing tendency in health care for the physician to simply inform the patient of the relevant medical information and allow the person to make his or her own decision. The contention is that the physician who allows his or her own experiences and preferences to be revealed will unduly influence the patient, thus obstructing his or her autonomy. This is called the independent choice model, which states:

...the "independent choice" model of decision making, [is one] in which physicians objectively present patients with options and odds but withhold their own experiences and recommendations to avoid overly influencing patients. This model confuses the concepts of independence and autonomy and assumes that the physician's exercise of power and influence inevitably diminishes the patient's ability to choose freely.⁶

The independent choice model is also referred to as the informative model where the professional simply provides information to the patient and allows him or her to choose without any professional guidance.⁷ Regardless of the name one chooses to call it, this model

⁶Quill, T., and Brody, H., "Physician Recommendations and Patient Autonomy: Finding a Balance between Physician Power and Patient Choice" *Annals of Internal Medicine* Volume 125, Number 9, (1996), pp. 763-769.

⁷Balint, J., and Shelton, W., "Regaining the Initiative: Forging a New Model of the Patient-Physician Relationship," *Journal of the American Medical Association*, Volume 275,

is the latest expression of what Ruth Macklin calls the basic dilemma of bioethics, namely “the potential conflict between patients’ rights [primarily those furnished by the principle of respect for autonomy] and their best interests [as perceived by the health care professional].”⁸ The current propensity, as indicated by this model, is to simply allow patients to make their own choices regardless of whether these decisions are in conformity with the physician’s conception of the patient’s best interests.

Typical forms of this conflict are demonstrated through the following case studies. The intention of presenting these cases is to show that the doctor-patient relationship is so complicated that simply informing patients and then deferring to their preferences, without a professional recommendation, in an attempt to respect their autonomy, is really the wrong thing to do under certain circumstances. It points at a fundamental difference between “patient authority” and “patient autonomy”. One aspect of respecting patient autonomy includes respecting the patient’s negative right to refuse treatment and also the positive right to information, thus, the informed consent requirement. However, patient authority is broader than respect for the principle of patient autonomy. It encompasses but is not limited to patient autonomy. Patient authority tries to capture the entire role of the patient in the clinical relationship, which includes autonomy and the patient’s negative rights, as well as the patient’s expression of his or her own best interests. It also requires a substantial amount of professional participation; thus distinguishing it from the informative and paternalistic models.

Number 11, (1996), pp. 887-891.

⁸Macklin, R., *Enemies of Patients*, (New York, Oxford: Oxford University Press, 1993), p. 238.

The following case studies will help show how important it is not to limit the patient's role by simply respecting the principle of autonomy and the right to refuse. The patient's role is much broader but requires the physician's assistance to develop. This type of collaboration is the essence of the authority model that I will develop.

Case One

A 38-year-old man, who had a mild upper respiratory infection suddenly developed a severe headache, stiff neck, and a high fever.⁹ He went to a local emergency room for help, where he was diagnosed with pneumococcal meningitis. The prognosis was that this type of bacterial meningitis is always fatal if not treated, in addition, any delay in treatment would result in permanent neurological damage. The physician assured the patient that he could be cured and that the appropriate treatment, for this type of meningitis, is a simple antibiotic injection. The attending physician explained the diagnosis and prognosis to the patient and emphasized how urgent it was that treatment be started. However, the man refused insisting that he wanted to be allowed to die.

Case Two

⁹Cassell, E., "What is the Function of Medicine?" in *Death and Decision*, ed E., McMullin (Boulder, Co.: Westview Pres, 1978), pp. 35-44.

Ricardo was 18-years-old with end stage kidney failure.¹⁰ He regularly missed his appointments for hemodialysis and indulged in an abusive diet which consisted of bags of potato chips and large amounts of Coca-Cola and beer. Because of these factors, Ricardo was often brought to the hospital in serious condition requiring emergency dialysis. On occasion the situation was so serious that relatives or friends would find him unconscious and have to rush him to the emergency room. Psychological evaluations revealed that Ricardo was impulsive and defiant but he was not suicidal. He simply believed that every time he was in trouble someone would find him and rush him to the emergency room.

Analysis of Case One and Case Two

These two brief cases help to illustrate the complexity involved in the doctor-patient relationship. Blind deference to patient wishes in an attempt to respect the principle of patient autonomy would give what appears to be the wrong approach to these cases. As Eric Cassel says, about the meningitis patient, “it would be a rare hospital where such a patient would not be treated against his will.”¹¹ Likewise, it is not at all clear that it would be appropriate to simply respect Ricardo’s wishes and allow him to continue with this reckless behavior, gambling that treatment would be available whenever he required it.

¹⁰Macklin, R., *Enemies of Patients*, p. 107.

¹¹Cassell, E., “What is the Function of Medicine?” *Hastings Center Report*, (December 1977). Of course there would have to be a psychological consultation to determine the patient’s competency and capacity to make such decisions. Nevertheless, Cassell suggests that the appropriate thing would be for the doctor to have the patient declared incompetent and provide the antibiotics.

The principle of respect for patient autonomy does not necessarily entail that one allows these two patients to continue on this self-destructive course. These examples help to demonstrate that there is a crucial role for the physician in the doctor-patient relationship, which has been neglected, or at least severely complicated, as a result of the well-developed autonomy movement. The recent debate over medical futility is motivated, in large part, by physicians' desire to recover some measure of decision-making power from their patients.¹² Likewise, this strong autonomy movement has, in some regards, limited the legitimate role of the patient as well. The patient is currently someone who is informed and then provides consent or refuses to provide consent. This limited understanding of the patient's role is partially responsible for the futility debate because it is assumed that the patient either has the right to make these types of decisions or does not. I argue that this is a very restrictive role and that the legitimate domains of both patient and professional authority need to be more clearly articulated.

It may be the case that patients will only trust doctors if they are assured that the physician retains some type of decision-making authority. If the assignment of decision-making authority is unclear, it may be more difficult to build and sustain trust. For instance, Tomlinson and Brody use the example of a physician who denies surgery to a patient on the grounds that he or she is a poor surgical risk. They say that:

The physician must be able to assert that the patient's life with angina is not

¹²Greiner, G., "The Physician's Authority to Withhold Futile Treatment," *The Journal of Medicine and Philosophy* Volume 20, (1995), pp. 207-224.

worse than death under the surgeon's knife [...]¹³

This type of restriction on the patient's wishes appears to be correct. When the patient's rights and best interests conflict with each other the professional has a complicated job. The professional's job will involve exercising his or her authority competently but it will also involve elevating the patient to a competent level of authority as well. This is not to say that the patient could never disagree with the physician; however, the disagreement must be rooted in substantive issues and not be the result of the patient's ignorance or the patient's mistrust of the professional. Therefore, by elevating the patient to a competent level of authority, the professional is, at a minimum, eliminating these corrupting factors.

Medicine was established on a promise to benefit (or at least to do no harm) to the patient and this is partly why patients turn to physicians for help when they are ill or injured.

In the above example, the simple fact that a person hates the pain of angina does not necessarily entail that the patient should undergo major surgery if he or she is a poor surgical risk. Likewise, in case one and case two, a physician should not allow a person to die of meningitis or kidney failure, in a misguided attempt to respect the principle of patient autonomy.

Thus, there is a very important role for the physician to play in the doctor-patient relationship, which the current interpretation of respect for the principle of autonomy does not allow for. Nonetheless, the patient also has a crucial role to play. The simple fact that a professional disagrees with a patient's decision or even thinks that it is foolish does not

¹³Tomlinson, T., and Brody, H., "Futility and the Ethics of Resuscitation," *Journal of the American Medical Association*, Volume 264, Number 10, (1990), pp. 1276-1280.

necessarily entail a threat to the proper role of the patient. There is a very important role for the patient to play in this relationship, which the current futility debate endangers.

The prevailing interpretation of the principle of respect for patient autonomy, and the predominant methods of approaching the medical futility debate, obscures these common-sense considerations. Some interpretations of autonomy conceal the proper role of the physician and the legitimate domain of professional authority, to the extent that some extreme autonomy positions would allow that the patient actually direct the course of treatment. The following quotation states some major concerns about the development of the principle of respect for autonomy and the confusion about the legitimate domain of professional authority:

It is possible to see the early history of bioethics as an effort to strip physicians of some of the enormous power they wielded over patients. The struggles over truth telling, informed consent, the nature of physicians' expertise, and patient autonomy attempted to transfer control from physician to patient. Autonomy became the rallying cry against the evil of physician paternalism, which can be taken as a synonym in this instance for illegitimate authority. The revolt against illegitimate uses of authority by physicians brought many benefits. *But the same revolt may have directed attention away from authentic and legitimate uses of authority by healers. The tendency to oversimplify, indeed to demonize, authority may have blinded us to its nuances and to the very real significance of authority - and power - in health care.* (Emphasis added)¹⁴

In addition to this concern over the proper domain of professional authority, I suggest that the prevalent interpretation of the principle of respect for autonomy, as manifested by the independent choice model, confounds the legitimate domain of patient authority, as well.

The intention of this chapter, therefore, will be to look at a current interpretation of

¹⁴Edwards, P., (ed) *Encyclopedia of Bioethics* (New York: Mcmillan Publishing, 1995), p. 211.

patient authority and professional authority and analyze some of the problems with these conceptions. Then I will proceed to discuss a theoretical framework for the concept of authority and show how this conception could be applied to the roles of the patient and physician. To do this, it will be necessary to clarify the differences between authority and power, and discuss the unavoidable aspect of inequality that is present in any authority relationship. From this theoretical discussion of authority the distinction between being “in authority” and being “an authority,” also will be explored. However, the main focus of this chapter is to simply introduce the ideas of patient and professional authority.

Preliminary Conception of Patient Authority and Professional Authority

Most authors agree that the doctor-patient relationship is a fiduciary one, in which the patient places trust in the physician and has rights, and the physician has corresponding duties.¹⁵ The following is a definition of a fiduciary relationship:

A fiduciary relationship exists whenever any person acquires a power of any type on condition that he also receive with it a duty to utilize that power in the best interests of another, and the recipient of the power uses that power.¹⁶

Cupples and Gochnauer¹⁷ explain that a fiduciary relationship arises when there is an intrinsic inequality of power, knowledge, resources or control. They say that when these conditions

¹⁵Macklin, R., *Enemies of Patients*, p. 4.

¹⁶Shepherd, D., *The Law of Fiduciaries*, (Toronto: Carswell, 1981), pp. 3-4.

¹⁷Cupples, B., and Gochnauer, M., “The Investigator’s Duty Not To Deceive,” *IRB: A Review of Human Subjects Research (A Publication of the Hastings Center)*, (1985), pp. 1-7.

of inequality arise the person in the power position is under a fiduciary obligation to act in the best interest of the person under his or her charge.

It has been suggested by commentators like Pippin and Englehardt that the professional authority of physicians is rooted in this fiduciary relationship which, as I have previously argued, is currently governed by the principle of respect for patient autonomy (and patient autonomy is protected by the doctrine of informed consent). This is the point that is suggested in the following quotation:

...the underlying assumption is that the authority of physicians basically stems directly from the consent of those affected [patients], on the rational expectation of the benefits that will follow.¹⁸

As the informed consent literature reveals, the presence of patient consent is one of the biggest factors in respecting patient autonomy.¹⁹ At a basic level, therefore, the idea of patient consent should be an adequate control that establishes and legitimates patient and professional authority. Of course, this is a two-way process. The patient has the ultimate authority to consent (or not to consent) and the professional has the authority to do whatever the patient consents to. However, Englehardt and Pippin express concerns about patient consent being a sufficient condition for patient and professional authority, in this relationship. Englehardt says:

[...]it is a model that permits all interventions to which the participants have

¹⁸Pippin, R., "Medical Practice and Social Authority," *The Journal of Medicine and Philosophy*, Volume 21, (1996), pp. 417-437.

¹⁹*President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*, p. 104.

consented, and it makes that permission the key element of all bioethics [...]²⁰

Pippin then goes on to say:

We would on such contractarian assumptions permit the sale of spare organs, all sorts of euthanasia, or assisted suicide, new industries like commercialized surrogate parenting, or voluntary experimental subjects, etc. (All as long as the putative great measure of legitimacy, consent, were not feigned, or coerced, or in some other sense non-voluntary.)²¹

Pippin and Englehardt's objections, to this conception of patient and professional authority, are very insightful. Clearly, on this model, the parameters of what the physician can do to the patient are only limited by the patient's consent and, by extension, the patient could consent to anything that he or she wants to. However, these consequences and the slippery slope that Englehardt and Pippin are concerned with are procedural problems that society could easily correct or prevent. Society could simply intervene and establish laws prohibiting some of the concerns that Pippin states. (This has already been done to a large extent, particularly concerning euthanasia and assisted suicide.) These are not objections to the principle of this model, namely, that professional authority is dependent upon patient consent, but are objections against the extremes to which this model could go.

The present debate about medical futility, however, presents serious difficulties for this conception of patient and professional authority. As we have already discussed, if a course of treatment is determined to be either qualitatively or quantitatively futile, commentators like Schneiderman and Jecker argue that the physician should have the authority to limit these treatments without the patient's or surrogate's consent. I have

²⁰Englehardt, H., *Bioethics and Secular Humanism: The Search for a Common Morality*, (Philadelphia: Trinity Press International, 1991) p. 107.

²¹Pippin, R., "Medical Practice and Social Authority," pp. 417-437.

proposed that it may be more appropriate to discuss patient and professional authority by stepping outside of the confines of the futility debate. However, the complexities of medical futility provide a serious challenge to any model of patient and professional authority that relies exclusively on patient consent. Therefore, I suggest that patient consent is definitely a necessary condition for professional authority but it is not, in itself, a sufficient condition.

Keeping this in mind, it is necessary to proceed with a brief theoretical discussion of authority in order to investigate how this can help clarify some other necessary conditions for patient and professional authority. The intention of this exercise is to establish the essential content of patient authority and professional authority in this unique relationship.

Authority and Power

Essential elements of any discussion of authority must address the distinction between authority and power and then address the aspects of inequality that are present in authority relationships. Authority and power are subtle and complicated notions that are often confused and are frequently used interchangeably; however, this common use is somewhat of a mistake because they are clearly distinct concepts. Essentially, a statement made by someone who has authority is generally more than advice but is less than a command; it is advice that one may not safely or wisely ignore.²² Pippin goes on to state that:

Authority relations are relations of inequality involving some sort of suspension of private judgment; in the cases we are interested in, a voluntary suspension, based on some assumption of superior competence, and usually

²²Pippin, R., "Medical Practice and Social Authority," pp. 417-437.

some fear of the bad consequences of acting “disobediently.”²³

Power, on the other hand, entails a threat of coercion that is not, and cannot be, present in authority.

Power, in one of its core meanings, is the ability to direct another’s action by implied or express threat of force. Authority has no necessary linkage to coercion and force.²⁴

Authority is deferred to because of an assumption of superior competence, whereas, power relies on the threat of coercion or force to gain compliance. Bertrand de Jouvenal wrote:

Authority is the faculty of inducing assent. To follow an authority is a voluntary act. Authority ends where voluntary assent ends.²⁵

The assumption of superior competence manifests itself in the form of voluntary assent and voluntary assent reflects the judgement that the authority figure should be obeyed or deferred to. Thus, the instructions of the authority figure reflect what the individual should do, whereas, power reveals what the individual is compelled to do. This proposes that authority claims have a normative component.

Authority and Equality

In any authority relationship there is a significant level of inequality. For instance, traditional authority relationships such as those between parent and child, or teacher and

²³Pippin, R., “Medical Practice and Social Authority,” pp. 417-437.

²⁴Edwards, P., *Encyclopedia of Bioethics*, (New York: Mcmillan Publishing, 1995), p. 207.

²⁵de Jouvenal, B. *De Sovereignty: An Inquiry Into the Political Good, Translated by J.F. Huntington* (Chicago University Press.) In Edwards, P. *Encyclopedia of Bioethics*, p. 207

student, or priest and parishioner clearly involve aspects of inequality. This inequality is based on an acknowledgment that the authority figure is so because he or she has a certain type of knowledge, or holds an appointment, that the other does not. This is part of the reason why the individual voluntarily chooses to allow such an important role to the judgement of the authority figure. The belief is that the suggestion of the authority figure should be deferred to, even if it conflicts with what the individual believes he or she should do.

Obviously, if one is going to suspend personal judgement and defer to the judgment of an authority figure, this should only be done for very good reasons. These reasons, by definition cannot include force or coercion, but must be based on some sort of acknowledgment of the authority figure's superior competence. Authority, therefore, is voluntary deference to the judgement of another because of an assumption of superior competence. I will argue that in the doctor-patient relationship there is superior competence on both sides but for different objects.

This leads to another distinction. There is a difference between being "in authority" and being "an authority."²⁶ The meaning of the phrase "in authority" basically refers to being in a position of authority. This type of authority is commonly explained through the way most political authority is explained: the existence of publicly approved rules, institutional procedures, the democratic process, etc. The phrase "an authority," however, refers to special qualities of the person. To be "an authority" the person must possess expertise and/or knowledge that present reasons to assume that this person merits having his or her judgement deferred to. The person who is "in authority" is so because of the position he or she

²⁷Pippin, R., "Medical Practice and Social Authority," pp. 417-437.

occupies, such as, policeman, political official, parent, etc. Whereas, the person who is “an authority” is so because of special characteristics, such as, expertise, knowledge or skill.

Introduction of the Authority of Doctors and Patients

Clearly, doctors are “in authority,” in the sense that they have institutionally defined roles that enable them to provide patient care. They are able to prescribe drugs (even narcotics), schedule expensive medical tests like blood-work or CT scans, they can even give someone the label of sick or disabled, which entitles that person to certain social benefits and/or costs. However, part of this ability comes from the fact that the physician is also “an authority.” The physician possesses unique skills, experience and knowledge that the patient, who is ill or injured, requires. Pippin explains his conception of the physician as “an authority” as follows:

However, a physician is also “an authority” [...] entrusted with authority by an ill or injured person not just because that physician is authorized or permitted to intervene, but, much more positively, because of a belief in the physician’s superior expertise, and (here a much more complicated point) because of some sort of trust that a physician will make use of such expertise beneficently, in consideration only or mostly of the patient’s welfare [...] ²⁷

The distinction between “in authority” and “an authority” relates back to the idea of the physician’s fiduciary obligations. The fiduciary qualities of the doctor-patient relationship result because the patient is actually dependent upon the physician for medical information

²⁸ Pippin, R., “Medical Practice and Social Authority,” pp. 417-437.

and must necessarily trust the physician to relay information in an open and meaningful way.²⁸

On the other hand, the idea of patient authority has a lot more to do with the patient's esoteric subjective knowledge about what is in his or her best interest. In this sense the patient is "an authority" in respect to determining his or her own best interests. In addition, however, the patient is also "in authority" in the sense that he or she has the ultimate legal right to withhold or provide consent.

This brief, theoretical discussion has set out some basic characteristics of authority. However, the intention is to discuss the idea of authority as it applies to patients and physicians. Therefore, the point of departure will be to simply apply these theoretical characteristics to the doctor and patient, without ascertaining whether they are in fact descriptive of their actual role and without asserting any normative claims about how patient authority and professional authority should be. The following description is simply a logical extension of the previous exercise.

If authority is as has been set out, in the previous discussion, then it would be analytically correct to assert that the professional authority of doctors would result in the following list: First, the goal of the physician's professional authority is to acquire voluntary deference to his or her judgement by the patient because of the patient's assumption that the physician has superior competence in these matters. Secondly, this authority relationship is unequal because the professional is "in authority" and is also "an authority." These properties are the primary basis for the fiduciary obligation of physicians, which gives the patient rights

²⁹Annas, G., Glants, L., and Katz, B., *Informed Consent to Human Experimentation: The Subject's Dilemma*, (Cambridge Massachusetts: Ballinger Publishing Company, 1977), p. 30.

and the physician corresponding duties. One of these duties is the third requirement, namely that the professional must be motivated by a commitment to the principle of beneficence.

In addition, if authority is as has been set out, in the previous discussion, then it is also correct to assert that patient authority would result in the following: Patient authority must concede the superior competence of physicians' technical skills and knowledge concerning medical matters. However, the patient can also claim that the physician must acquiesce to the patient's claim to superior competence and knowledge concerning his or her own best interests. The patient's authority will be asserted in an unequal relationship, in which the physician is "in authority" and is also "an authority." Therefore, part of the patient's authority has to do with the physician's fiduciary obligation to act in the patient's best interest, because the patient is also "an authority" when it comes to determining his or her best interests and is "in authority" in that he or she has the ultimate discretion of whether to consent or not.

The essence of legitimate authority is that it requires voluntary deference to the authority figure's judgment because of a belief in superior expertise. Therefore, the authority of the professional would require voluntary deference to his or her judgment, by the patient, to technical medical matters. Whereas, patient authority would require voluntary deference to his or her judgment, by the professional, to subjective matters pertaining to his or her best interests.

Of course, disagreement is always possible and either the patient and/or the professional may refuse to respect the authority of the other; however, this does not diminish the normative goal of articulating exactly what professional and patient authority should be in the doctor-patient relationship.

The above is simply a description of how patient and professional authority could be conceived. The difference between power and authority is that power implies some type of coercion. This could be as simple as the professional being selective about what he or she tells the patient in order to ensure that the patient agrees to the course of treatment that the professional believes is best. This is similar to the paternalistic model. The paternalistic professional would simply tell the patient what he or she needed to, in order to get the patient to agree to what the professional thought was best. The paternalistic model is a good example of the exercise of “power” and not “authority.”

Likewise, the informative model is not an example of authority or of power because the professional does not assert any judgment whatsoever. This approach is as harmful as the paternalistic approach because it does not allow the physician to exercise judgment but requires the patient to employ his or her choice without any professional guidance. The legitimate exercise of authority requires both parties to defer to the superior competence of the other. If the professional’s recommendation is not forthcoming then there is nothing to regulate the choices of the patient except for neutrally presented information. An authority model, on the other hand, would require the professional to elevate the patient to such a level that the patient voluntarily defers to the professional’s judgment because of a belief that the professional would have superior judgment (in the sense of more competent) in these matters.

I will show in the coming chapter that one of the foundational values of patient authority is the prerogative to define what is in his or her own best interests. I will elaborate on the ideas of patient authority and professional authority. My intention in the preceding section was simply to introduce the different conceptions, because concerning patient

authority in particular there will probably be confusion with the idea of the principle of respect for patient autonomy. As the coming chapter will illustrate, however, the principle of respect for patient autonomy is only one aspect of patient authority, since the latter also includes considerations about the patient's best interest and substantial professional input. Therefore, it is essential to understand that legitimate authority, either patient or professional, requires an intermixing which cannot be legitimately exercised in isolation or unilaterally.

Chapter Four

Discussion of Patient Authority and Professional Authority

The current debate about the idea of medical futility has generated a substantial amount of confusion about the proper roles of both the doctor and the patient in this relationship and the appropriate domain of each party's decision-making authority. There are two extremes that this debate oscillates between: namely, the ideas of unilateral decision-making authority for either the patient or professional. In regard to patient unilateral decision-making, the general concern is revealed through the following quotation:

It was suggested that a victory for Mr. Wanglie would mean that patients or their families could demand whatever treatment they wished, regardless of its efficacy.¹

Likewise, concerning unilateral professional decision-making authority Veatch explains one of the main concerns in the following:

The alternative is to hold that even though a treatment that would prolong life is desired by a patient, the physician can judge that the patient would be better off dead. I don't know how anyone can have the hubris to inflict death paternalistically on a patient against his or her wishes.²

¹Angell, M., "The Case of Helga Wanglie: A New Kind of 'Right to Die' Case," *The New England Journal of Medicine*, Volume 325, (1991), pp. 511-512.

²Veatch, R., "Why Physicians Cannot Determine If Care Is Futile," pp. 871-874.

The two positions of (1) unrestrained patient demands and (2) unrestrained professional paternalism have obscured the appropriate domains of both patient authority and professional authority. The basic composition of authority is that it requires voluntary assent to the authority figure's judgment. Where voluntary assent ends, authority ends. Therefore, my intention is to provide a critical description of the legitimate domains of both patient authority and professional authority. The aim is to analyze the criteria which constitute the concepts of patient authority and professional authority, in order to approach the futility debate from this new angle (authority).

Patient Authority

There are two main values which have been traditionally accepted as constituting the foundation of the doctor-patient relationship and it is these values that I suggest also constitute the foundations of patient authority: namely, the patient's best interests and the principle of respect for autonomy.³⁻⁴ These two values are in many respects compatible. For instance, health care institutions often encourage patients to create advance directives or designate someone as a proxy(who knows the patient's wishes). The reasoning behind this type of incentive is to promote the principle of respect for patient autonomy even though patient participation is not possible.

³Macklin, R., *Enemies of Patients*, p. 238.

⁴*President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*, p. 42.

However, these two principles can also conflict, as I have mentioned before, this conflict is what Ruth Macklin calls “the basic dilemma of Bio-ethics,” namely, the potential conflict between a patient’s best interests and the principle of respect for patient autonomy. One example of the potential conflict would be that the health care professional believes that one course of treatment would be in the patient’s best interests but the person disagrees and refuses to provide consent, thus exercising his or her negative right to refuse treatment. The appropriate task would then be to reconcile what the physician thinks is best for the patient with what the patient thinks is in his or her own best interest. Likewise, the current futility debate presents this same conflict, but inverted. The professional believes that withholding or withdrawing treatment is in the patient’s best interest, whereas, the patient (and/or the patient’s family) disagree and wish to exercise decision-making power to impose their own subjective values and force professionals to provide treatment.

Patient’s Esoteric Subjective Knowledge and the Patient’s Best Interests

One of the fundamental goals of medicine is to promote the patient’s health-related best interests. Over the years several ways of assessing the patient’s best interest have developed. For instance, there is the paternalistic approach which states that the physician should determine unilaterally what is in the patient’s best interests.⁵ This approach is not widely accepted but did constitute the foundations of medical practice until recently (1970's

⁵Emanuel, E., and Emanuel, L., “Four Models of the Physician-Patient Relationship,” pp. 2221-2226.

and early 1980's). There is also the "independent choice" model which allows the patient to decide on his or her own without the doctor influencing the decision one way or the other. There is evidence in the literature that this approach is being implemented more and more frequently.⁶⁻⁷ Another method is the shared decision-making approach which Jay Katz and the President's Commission advocate. Shared decision-making argues that the patient should have an active role in making these best interest determinations, but this approach also requires that he or she come to these decisions through a shared decision-making process with the physician. By utilizing the physician's unique medical knowledge and experience it is hoped that the patient will reach the most appropriate decisions possible, that is, a decision that takes into consideration the relevant medical information and also the patient's subjective considerations as well.

Regardless of the method one chooses, there is a good argument that suggests that the patient offers a unique and crucial perspective to the medical decision making-process. Patients have esoteric knowledge of their own values that cannot be known by anybody else, except as revealed through conversation with the patient. It is this esoteric subjective knowledge, possessed by the patient, which highlights the relevance of his or her role in the decision-making process. The President's Commission says:

Determining what constitutes health and how it is best promoted also requires

⁶Quill, T., and Brody, H., "Physician Recommendations and Patient Autonomy: Finding a Balance between Physician Power and Patient Choice," *Annals of Internal Medicine*, Volume 125, Number 9, (1996), pp. 763-769.

⁷Charles, C., Gafni, A., and Whelan, T., "Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model," (Centre for Health Economics and Policy Analysis, McMaster University, 1998), p. 14.

knowledge of patients' subjective preferences. In pursuit of the other goals and interests besides health that society deems legitimate, patients may prefer one type of medical intervention to another, may opt for no treatment at all, or may even request some treatment when a practitioner would prefer to follow a more conservative course that involved, at least for the moment, no medical intervention.⁸

To make this point, the Commission uses several examples: a person with a slipped disc; a person with an injured knee whose prognosis is that surgery has a 30% chance of reducing pain but will not relieve it completely; and a baseball pitcher who has persistent inflammation of his elbow. In each of these situations, the goal is to improve the patient's health. However, medicine has tremendous uncertainties and it is often unclear which is the best course of treatment. Therefore, the patient's esoteric subjective knowledge becomes relevant in determining his or her own best interests. For instance, the person with a slipped disc may prefer surgery because he or she is easily depressed and does not want to take a chance of a relapse by being isolated and confined to bed. Or the person with an injured knee may prefer to live with the condition and modify his or her lifestyle instead of accepting the possible risks of surgery for relatively minor benefit. Likewise, the baseball pitcher may prefer to take cortisone on a continuous basis even though a new position on the team would cure the problem permanently.

The Commission's point is simply that the professional will have his or her own preference, based on complicated clinical knowledge and should make a professional recommendation to the patient. Nevertheless, it is ultimately the patient who should decide

⁸*President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: The Ethical and Legal Implications of Informed Consent in the Patient Practitioner Relationship*, p. 43.

according to the medical information (provided by the professional) and his or her own subjective knowledge about what is in his or her own best interest. The patient possesses certain esoteric subjective knowledge which enables him or her to decide which of the available alternatives is most fitting and compatible with his or her life goals.

Esoteric Subjective Knowledge and the Principle of Respect for Patient Autonomy

This leads to the second value of patient authority, the principle of respect for patient autonomy. Allan Goldman explains the intrinsic value that individuals place on the principle of respect for autonomy in his article "Refutation of Medical Paternalism":

Personal autonomy over important decisions in one's life, the ability to attempt to realize one's own value ordering, is indeed so important that normally no amount of other goods, pleasures or avoidance of personal evils can take precedence.⁹

As the preliminary discussion of informed consent explained, the current recognition of the principle of respect for patient autonomy is that it manifests itself as a negative right which allows patients to refuse treatment, so long as they are informed and competent. As a result, treatment refusals and the rejection of a professional recommendation are clearly within the proper domain of patient autonomy. This type of patient autonomy even extends to the person's refusal of life-sustaining treatment, where numerous court cases have affirmed the right of a competent patient to refuse any treatment including those which are life-

⁹Goldman, A., "The Refutation of Medical Paternalism," pp. 58-66

sustaining.¹⁰

This is evidenced in the Canadian case of *Nancy B* (1992)¹¹, who was a 25-year-old woman who suffered from generalized polyneuropathy for a prolonged period of time, as the result of Guillain-Barré disease. She was respirator dependant and her prognosis was very poor, and was not expected to improve. She continuously requested that the respirator be withdrawn, and psychological examinations demonstrated that she was competent to make these types of decisions. However, the hospital in which she was a patient refused to disconnect the respirator, without first seeking legal direction and protection. Nancy B then initiated legal action for an injunction permitting her physician to withdraw the respirator. Mr. Justice Dufour of the Québec Superior Court granted the injunction and the respirator was withdrawn. Nancy B died on February 13, 1992.

Justice Dufour concluded the following:

[...] the “logical corollary of [the] doctrine of informed consent is that the patient generally has the right not to consent, that is the right to refuse treatment and to ask that it cease where it has already been begun.” Furthermore, this right encompasses the informed and freely given refusal of life-sustaining treatment, such as the use of a respirator.¹²

This example demonstrates, that patients must be given the right to decide what is in their

¹⁰Gostin, L., “Deciding Life and Death in the Courtroom: From Quinlan to Cruzan, Glucksberg, and Vacco—A Brief History and Analysis of Constitutional Protection of the ‘Right to Die’,” *Journal of the American Medical Association*, Volume 278, Number 18, (November 1997), pp.1523-1528.

¹¹Fish, A., and Singer, P., “Nancy B.: the Criminal Code and Decisions to Forgo Life-Sustaining Treatment,” *Journal of the Canadian Medical Association*, Volume 147, Number 5, (1992), pp. 637-642.

¹²*Nancy B. v Hotel-Dieu de Quebec et al* (1992), 86 DLR (4th) 390, 392 (Que Sup Ct)

personal best interests, as opposed to someone else deciding for them. As a result of this principle, respect for patient autonomy, patients have been furnished with a negative right which entitles them to refuse unwanted medical treatment.

In addition to the *Nancy B* case, which presents the issue from a Canadian perspective, there is also the U.S. Patient Self-Determination Act. This act went into effect on December 1, 1991¹³ and was the first U.S. federal legislation regarding life-sustaining treatments and advanced directives. This federal law requires health care facilities funded under Medicaid or Medicare to notify competent adult patients of their rights, including the right to refuse or accept treatment and the prerogative to execute an advance directive. The intention of the Patient Self-Determination Act is to encourage but not require patients to fill out advance directives, which are documents such as a living will that state the person's treatment preferences; and/or proxy appointments, which are documents such as a durable power of attorney that appoints a proxy decision maker, in the event of future decision-making incompetence.

The Patient Self-Determination Act has generated a wealth of literature, of its own. However, my intention is not to evaluate this literature but rather to emphasize the theoretical justification for this document by quoting what Susan Wolf states as the ultimate basis for the implementation of this statute:

There is widespread agreement that directives can have many benefits. These include improved communication between doctor and patient, increased clarity about the patient's wishes, and ultimately greater assurance that

¹³Wolf, S., et al., "Patient Self-Determination and Advance Directives," *New England Journal of Medicine*, Volume 325, Number 23, (1991), pp.1666-1672.

treatment accords with the patient's values and preferences.¹⁴

These concerns about (1) communication between the doctor and patient, (2) patient wishes and (3) patient values, reveal the importance placed on the patients participation and the relevance of the patient's esoteric subjective knowledge in determining his or her own best interest. This is because it is recognized that the medical intervention that will promote the patient's best interest usually rests on a subjective judgment about the individual patient.¹⁵ It is the guarantee of this type of esoteric subjective knowledge that the principle of respect for autonomy tries to grant. It currently does this by furnishing the patient with the negative right to refuse treatment, despite possible professional objections to the contrary.

Summary of Patient Authority

The idea of patient authority encompasses the notions of (1) the patient's best interests, (2) respect for the principle of patient autonomy and (3) a negative right to refuse treatment. The patient's legitimate exercise of this type of authority requires the physician's voluntary assent. The literature reveals that physicians readily defer to patients subjective determinations of their own best interests, they respect the principle of patient autonomy, and in almost all excepting futility cases, they support the patient's rights concerning treatment

¹⁴Wolf, S., et al., "Patient Self-Determination and Advance Directives," pp. 1666-1672.

¹⁵*President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship* (Washington, D.C: U.S. Government Printing Office, 1982), p 44.

preferences. The idea of medical futility raises concerns here because it obscures the distinction between the patient's negative right to refuse treatment and a potential positive right to insist on medical treatment that has been labelled futile.

Medical Futility, the Uncertainty and the Need for Professional Authority

The current debate about medical futility presents new dimensions that must be considered in relation to patient authority. One particular aspect of medical futility is that it proposes to extend the negative right (to refuse treatment) into a positive right to insist on treatment. This is illustrated through cases like Helga Wanglie¹⁶ and Catherine Gilgunn¹⁷, where the patient's family (on behalf of the compromised patient) insisted on treatment that the professional was not willing to give, because in his or her professional opinion continued treatment was futile.

As the *Nancy B* case and the Patient Self-Determination Act reveal, it is very important for patients to have a substantial role in determining the appropriate course of medical treatment, because it is only the patient who has the requisite esoteric subjective knowledge to evaluate the benefits of treatment. A comparison of the *Nancy B* case to one of the issues produced by the idea of medical futility raises a particularly important point. The judge's decision in *Nancy B* states "[...] the patient generally has the right not to consent, that

¹⁶Miles, S., "Informed Demand for "Non-Beneficial" Treatment," pp. 512-515

¹⁷Capron, A., "Abandoning a Waning Life," *Hastings Center Report*, (July-August, 1995), pp. 24-26.

is the right to refuse treatment and to ask that it cease where it has already begun.”¹⁸ In contrast, the *Wanglie* case, which is a paradigm medical futility case, reveals that the health care professionals encouraged Mrs. Wanglie’s family to exercise this negative right, on her behalf. When the family did not wish to exercise this negative right, the health care professionals insisted that the family did not have a “positive right” to insist on futile treatment (namely, the treatment that was being provided to Mrs. Wanglie).

The important point is that by refusing to exercise their negative right the family was automatically accused of exercising a positive right to demand treatment. However, the family did exercise their negative right, basically by refusing to consent to the removal of treatment the family was exercising their right they simply chose not to refuse. Any meaningful right must be one in which the person is free to exercise or not (free speech is a good example of this). Of course, a consequence of this refusal to exercise a negative right is that the professionals were then obligated to provide treatment that they believed was futile. However, this is parallel to the previously discussed *Quinlan* case where the professionals were compelled to stop providing treatment that they thought was beneficial. Clearly, patients are entitled to refuse beneficial treatment, but they are not necessarily entitled to insist on futile treatment. However, the practical problem is that the same act entails both of these consequences. In essence, the refusal to exercise the negative right (to refuse) has the consequence of exercising a positive right (to insist on treatment).¹⁹

¹⁸*Nancy B. v Hotel-Dieu de Quebec et al* (1992), 86 DLR (4th) 390, 392 (Que Sup Ct).

¹⁹It is important to note that this subtle distinction applies primarily to cases where the futile treatment has already commenced, and the question is whether to stop it. In other

The problem arises because, patients and/or their surrogates, contest whether the treatment, that the professionals have labelled futile, is really futile. When the benefits of the treatment are challenged, it has already been conceded, to a large extent, that patients are the most appropriate people to decide, according to their esoteric subjective knowledge, whether treatment is beneficial or not. Regardless, the new controversy concerning medical futility has rendered the legitimate domain of patient authority unclear. However, if there are grounds to extend patient authority to include a positive right²⁰, then this right will most likely rest upon some conception of professional authority. Professional authority is involved because (1) legitimate patient authority requires the physician's voluntary deference to his or her judgment, and (2) there is a technical medical matter involved, namely the providing or withdrawal of treatment. Determining whether treatment is beneficial is not a technical matter, however the actual implementation or the removal of treatment is. Therefore, the crossing from the realm of negative rights into the domain of positive rights will require even more rigorous communication efforts on the part of the physician and, of course, increased responsibility. Unilateral decision-making on the part of, either the patient or the professional

cases, however, where the patient has not received the relevant treatment, the above described transition from the negative right of refusing to consent to the positive right to insist on futile treatment is not as clear.

²⁰There may be a difference between positive patient rights and a positive right to demand futile treatment. If the doctor and patient agree that treatment is appropriate then patients, obviously, have the positive right to demand it. The Tuskegee case is an example of this. (The tuskegee experiment involved 400 black males with late-stage, untreated syphilis and approximately 200 controls free of the disease. When penicillin was discovered as a cure for syphilis it was intentionally kept away from the participants. King, P., "The Dangers of Difference: The Legacy of the Tuskegee Syphilis Study," *Hastings Centre Report*, Volume 22, Number 6, (1992), pp. 35-38.) However, it is not clear that the same positive right would exist to insist on futile treatment.

appears to be unacceptable.

Aspects of Professional Authority

For the first time in history the physician has access to technology and medications that really do heal or ameliorate a vast range of disease conditions.²¹ In addition, it is only a physician who is authorized to diagnose and treat various illnesses or injuries. This is largely due to his or her specialized training, which equips the physician with specific knowledge, experience and skills. This is the reason why an ill or injured individual seeks the assistance of a physician. The physician's technical expertise and highly specialized knowledge partially justify the patient in deferring to the physician in matters where the physician has unique skills and relevant knowledge and experience. In this respect Byrne explains the significance of the physician's technical skills and unique knowledge in relation to decision-making, within this distinctive relationship.

If they [physicians] are not better qualified to make medical decisions than patients, they are unfit to practice. Their experience and training is, or ought to be, not such as to leave them simply as technicians, suppliers of information and skillful executors of others' instructions.²²

Technical expertise and specialized knowledge are the most important attributes of a physician. As we have seen from the theoretical discussion of authority, one central aspect

²¹Shorter, E., "The History of the Doctor-Patient Relationship," in *Companion Encyclopedia of the History of Medicine* Volume 2 Bynum, W., and Porter, R., (eds.) (London and New York: Routledge) p. 792.

²²Byrne, P., "Authority, Social Policy, and the Doctor-Patient Relationship," In *Doctor's Decisions: Ethical Conflicts in Medical Practice* p. 229.

of professional authority is the patient's voluntary deference to the professional, based on an assumption of superior competence. Obviously, the professional's competence is superior to the patient's in regard to these very specific medical matters. Otherwise, there would be no benefit in soliciting the help of a physician when the patient is ill or injured.

However, the mere presence of technical expertise, clinical experience, and specialized knowledge is not a sufficient justification for professional authority, although it is definitely a necessary condition. For instance, there could be a technically competent physician who is very ambitious and is only concerned with research. He or she may only care about research findings and not about patients or research subjects. Of course, not all researchers are like this, although cases like the *Jewish Chronic Disease Hospital* case, where researchers injected cancer cells into patients under the pretense of treatment and without consent, raise enough concern to suggest that technical competence and specialized knowledge are necessary conditions for professional authority but are not sufficient conditions.

As mentioned earlier, in a quotation by Pippin, there is a definite need for the physician to have a commitment to the principle of beneficence (the patient's best interest), in addition to his or her technical skills and knowledge. The principle of beneficence requires the moral agent to take positive steps to help others.²³ This is fundamental because the patient would not trust the physician if he or she were motivated solely by economic considerations or if the physician was more concerned with research and experimentation than with the beneficial treatment of patients. The typical patient who ends up in an emergency

²³Hilberman, M., et al., "Marginally Effective Medical Care: Ethical Analysis of Issues in Cardiopulmonary Resuscitation (CPR)," *Journal of Medical Ethics*, Volume 23, (1997), pp. 361-367.

room, rightly expects that the health care professionals want to help. The person does not intend to participate in an experiment or some other research project.²⁴ If the professional's primary intention is to help, and he or she has the required skills and knowledge, then in particular areas the patient will be justified in voluntarily deferring to the professional.

But technical skills, experience, specialized knowledge, and a commitment to the principle of beneficence are still not sufficient to justify professional authority. The traditional paternalistic physician possessed these characteristics; in fact, the whole problem with paternalism is that the professional believes that he or she knows what is in the patient's best interests better than the patient does. So clearly an additional element of interpersonal skills and an ability to communicate effectively is also required.

Interpersonal skills will enable the physician and patient to communicate in an open and constructive manner, which will help create trust and ensure patient understanding. The patient who is ill or injured does not possess the clinical expertise and experience that the physician possesses. Therefore, the patient is dependent upon the physician (for this special knowledge) and the physician must be able to relate this vital information to the patient so that he or she can make an informed choice. The following quotation explains this situation nicely:

In other words, we authorize physicians to tell us, in effect, what we are authorizing them to do. When it is a question of alternative treatments, "quality of life" evaluations, risk assessments and so on, physicians do not merely transmit information. We must even depend on them to help us find

²⁴Although if the patient is made aware that this is an option, he or she certainly has the right to participate. My point is simply that the physician cannot treat the patient under the pretense of treatment but really be doing research or an experiment.

ways to be able to disagree with them.²⁵

Thus, as a minimum the physician must be able to relate the complicated medical information to the patient, in such a way that the patient can understand it and weigh it in accordance with his or her other life goals.

Professional Authority and Interpersonal Skills

The essential content of professional authority thus includes: (1) specialized knowledge with technical skills, (2) a commitment to beneficence, and (3) interpersonal skills. The essence of specialized knowledge and technical skills is fairly obvious. The doctor must be knowledgeable and technically competent and this is determined or proved through graduation from medical school and the gaining of a medical license and/or recognition from the Royal College of Physicians and Surgeons of Canada.

A commitment to beneficence has been part of the profession since the times of Hippocrates whose oath clearly states that the doctor must aspire to help the patient or at least to do no harm.²⁶ This requirement is central to the futility debate, namely, the ambiguity about whether the professional is helping the patient when he or she denies futile treatment against the patient's wishes, or whether the professional would be harming the patient by providing treatment that he or she [the professional] thought was futile, even though the

²⁵Pippin, R., "Medical Practice and Social Authority," pp. 417-437.

²⁶ Hippocrates, *Hippocrates Galen: The Oath* in Hutchins, R., *Great Books of the Western World*, (Chicago: Encyclopaedia Britannica, Inc., 1952), p. xii.

patient and/or family requested it.

It is the last requirement, interpersonal skills, that can help resolve this ambiguity about a commitment to beneficence. As the President's Commission stated: a determination of what will help a patient depends largely upon a subjective determination, by the patient. This is also the basis of the informed consent requirement. Thus, another ambiguity about interpersonal skills is its relation to the requirement of patient consent. This notion was introduced in the section "Preliminary Conception of Professional Authority." That model of professional authority stated that the professional has the authority to do whatever the patient consents to. Clearly, interpersonal skills are required in order to get the patient's consent and to ensure that it is an informed consent. Without discussion and information conveyed in an understandable and meaningful manner, consent could not be obtained. Thus, one necessary condition of interpersonal skills is effective and understandable communication. The hope is that if the relevant information is related in this manner and the patient and physician have the same goals, then the patient will consent.²⁷

Despite effective communication, in specific situations in which the patient has made a poor decision, the patient's informational status is incomplete without a professional recommendation, and an explanation why the professional thinks that this is the most appropriate course of action. By poor decision, I am referring to situations like case one and

²⁷By the patient and physician having the same goals, I am talking about the subjective preferences of the patient. If the doctor and patient agree that the goal is, say to restore health, they can work to accomplish that goal. But if the physician's goal is to restore health and the patient has another goal, perhaps live a shorter life outside of hospital than to restore health at the expense of a lengthy hospital stay, they do not have the same goals.

case two, which were mentioned in the previous chapter.²⁸ Instances like these reveal that the patient may be informed of the appropriate risks, benefits and possible alternatives, but lack a professional recommendation should vitiate the patient's consent. For instance, in the earlier sections case one and case two, the physician would actually be negligent (perhaps not legally, but ethically) if he or she did not strongly recommend an appropriate course of treatment to the patient. The independent choice model appears to hurt patient authority rather than promote it, at least in these specific cases. Therefore, I suggest that a professional recommendation adds to the patient's ability to make an informed decision and that its absence does more harm than good.

Of course, in cases where a patient quickly reaches a sensible decision, there may be no need for a professional recommendation. Nevertheless, as the seriousness of the situation increases so should the need for a professional recommendation. Even in the *Nancy B* case, where she was entitled to refuse treatment despite institutional or professional disapproval, the physician should be required to recommend one way or the other, and if he or she disagreed with Nancy B then this disagreement should be worked through.²⁹

Another important aspect of interpersonal skills is the ability of the physician to accommodate disagreement, in this relationship. In most adult relationships some form of

²⁸You will recall that "case one" dealt with a man suffering from meningitis but refused simple penicillin treatment and "case two" was about Ricardo, the rebellious youth suffering from end stage kidney failure.

²⁹The nature of the injunction in the *Nancy B* case implies that she had discussed this decision with her physician(s) and it was a responsible calculated decision. The physician's reluctance to participate in the removal of her respirator was most likely because of institutional policies. Not because of disagreement between the doctor and patient.

disagreement is inevitable, especially when the relationship is based on paramount issues, such as, restoring or maintaining an individual's health; or more important, when caring for a person who is going to die. In these cases the person is passionately interested and often has very good reasons for his or her opposition to the doctor's professional recommendation, namely, his or her esoteric subjective knowledge. Jay Katz argues that disagreement, in this relationship, must be embraced rather than avoided.³⁰ As a result, the way disagreement is coped with, in the doctor-patient relationship, is of the utmost importance.

There are two important considerations concerning disagreement in the doctor-patient relationship. The first concerns the attitude of the doctor toward disagreement and the second concerns the attitude of others toward the doctor when there is disagreement. The first consideration about the physician's attitude toward disagreement is that refusing to allow for it could lead to silence and a lack of communication, which in turn would compromise trust. The patient may fear justifiedly or not that challenging the professional or disagreeing with him or her is forbidden and will lead to compromised care or even transfer (often interpreted as abandonment). In an attempt to avoid conflict or disagreement the physician may simply not discuss certain issues with the patient and if they are discussed it may be in a manner where disagreement would be discouraged.

Professor Katz has exposed the oldest strategy for avoiding doctor-patient conflict - silence. If the physician presents herself as certain of the one right course, and fails to divulge the range of options and the uncertainties that

³⁰Katz, J., *The Silent World of Doctor and Patient*, (New York, Free Press, 1984), p. 99.

attend each, there is little to discuss.³¹

As Pippin said, in his article "Medical Practice and Social Authority," we must even depend on doctors to reveal ways that we can disagree with them. So if the physician decides to remain silent because of potential disagreement, the patient is reduced from an autonomous agent to someone who is ignorant of the intended course of treatment and dependent upon the physician, the number of decision-makers is reduced from two to one.

Katz anticipated the complications associated with avoiding disagreement and promoting silence within this relationship. One of the main issues of the current futility debate is this very issue of silence; physicians' desire to make these decisions unilaterally without patient participation. This desire reveals that the physician does not want to confront, head-on, all the complications that would be involved in gaining the patient's informed consent. As a result, they argue that they should be entitled to make these decisions without patient consent or even patient awareness.³²

The second concern about disagreement in this relationship is the attitude toward the physician. Some people (patients, risk management personnel, CEOs etc.) may see disagreement as a lack of skill on the part of the physician. Wolf states:

The prevailing notion is that if the clinician is skilled enough, the patient can be managed and conflict prevented. When conflict surfaces, especially in an encounter between a junior physician and a patient, that may be blamed on the

³¹Wolf, S., "Conflict Between Doctor and Patient," *Law, Medicine & Health Care*, Volume 16, Number 3-4, (1988), pp. 197-203.

³²I do not suggest that doctors are not entitled to make these decisions, neither do I argue that they should make these decisions. I am suggesting that this tendency towards silence has serious complications and difficulties. The futility debate is a manifestation of some of the difficulties associated with silence.

physician's lack of skill; if only she were more able, there would be no conflict at all.³³

Both of these approaches are less than satisfactory. Disagreement in this relationship should not be viewed as a sign of failure, on the part of the physician to be dreaded or avoided. Nor should it produce anxiety and fear in the patient. Disagreement should be thought of as a sign of two people struggling to make good decisions in very complicated circumstances. I suggest along with Katz and Wolf that conflict is inevitable and that it can usually be resolved within the confines of the doctor-patient relationship. Cases like *Quinlan* and *Wanglie* reveal that the primary concern was not about making good decisions but was about who should have the authority to make the final decision. Marcia Angell explains this concern:

Since the Quinlan case it has gradually been accepted that the particular decision is less important than a clear understanding of who should make it, and the Wanglie case underscores this approach.³⁴

I contend, however, that the concern in this relationship should not be "who has the ultimate decision-making authority?", but rather the focus should be on "how the decision is made." Clearly there are very compelling reasons to defer to patient authority in some situations while in other situations it would be more appropriate to defer to the professional. Therefore, the conception of interpersonal skills that I argue for, involves the physician's ability to communicate effectively with the patient, a professional recommendation and the physician's acceptance of disagreement (and a commitment to work that disagreement out

³³Wolf, S., "Conflict Between Doctor and Patient," pp. 197-203.

³⁴Angell, M., "The Case of Helga Wanglie: A New Kind of 'Right to Die' Case," pp. 511-512.

within the confines of the doctor-patient relationship). The hope is that instead of worrying about “who” is entitled to make the final decision, the professional and patient will endeavor to work together to make “good” decisions. Working through all the complexities and obstacles that this involves.

Summary of Patient and Professional Authority

The actual model of the doctor-patient relationship that has been developed in the preceding sections is diagramed in the following conceptual model: Figure One:

Elements of the Doctor Patient Relationship

Patient Authority (Exists prior to the clinical encounter) • Esoteric subjective knowledge which enables the patient to determine his or her own best interests. • Endowed with liberty and autonomy to implement his or her order of value in his or her own life • A negative right to refuse unwanted interference with bodily integrity (e.g., right to refuse unwanted medical treatment.)
Professional Authority (Exists prior to the clinical encounter) • The professional has special medical knowledge and technical skills. • The professional has a commitment to the principle of beneficence (i.e., the commitment to act in the patients best interests.) • The professional's interpersonal skills which include: effective communication skills, a professional recommendation and an acceptance of disagreement and a serious attempt to reconcile that disagreement.

This model of patient authority has three components: (1) esoteric subjective knowledge concerning his or her own best interests, (2) respect for the principle of patient autonomy, which, in this unique relationship, involves the fiduciary obligation of the physician and the need to be sufficiently informed in order to provide an informed consent, and (3) a negative right to refuse unwanted medical treatment.

The model of professional authority is threefold: (1) the physician must have the

required knowledge and be technically competent, (2) be committed to the principle of beneficence, and (3) possess the required interpersonal skills. The term “interpersonal skills” consists of an additional three components: (1) effective communication skills, (2) a professional recommendation, and (3) an acceptance of disagreement and a serious attempt to reconcile that disagreement within the confines of the doctor-patient relationship.

This model rationalizes patient and professional authority, however, it does not state exactly what either has the authority to do. First, I suggest that the professional possess the decision-making authority to have his or her judgment deferred to because of an assumption of superior competence, based upon the premise that he or she is “in authority” and is also “an authority.” This, of course, is dependent upon the physician being technically competent and knowledgeable, committed to the patient’s best interest and possessing the required interpersonal skills.

Secondly, the patient has the authority to evaluate the medical information in relation to his or her subjective knowledge about what constitutes his or her best interests. Since the professional must be committed to the patient’s best interests he or she must seriously consider what the patient requests and provide sufficient information, including a professional recommendation, to elicit an informed consent.

Patient authority, as I have been arguing, requires the professional to invite the patient to participate fully in the decision-making process. The professional must elevate the patient to a level of competence where he or she is able to make a “good decision” and not simply an independent decision. The ‘independent choice’ model does not allow for the physician to have any type of authority in the decision-making process. The relationship between the

‘independent choice’ model and the futility debate reveal the possible extremes that decision-making in the doctor-patient relationship can oscillate toward. At one extreme is the paternalistic model, where the physician makes all the decisions and at the other is the independent choice model, where the patient is the final decision-making authority. The futility debate has serious implications here because both positions imply a communication disruption between the doctor and the patient. The problem of futility presents irreconcilable differences between the patient (or family) and the health care professional, as was demonstrated in the *Wanglie* case. The model of patient and professional authority that I have been developing attempts to establish authentic and legitimate domains for both the patient and professional in this unique clinical relationship. Professional authority stems from helping patients make “good decisions” by enhancing their authority instead of simply presenting the relevant information while withholding a professional recommendation. The independent choice model diminishes patient authority and so does the paternalistic approach.

In regard to the current futility debate a professional recommendation is an indispensable component of respecting patient authority. The silence that is promoted by the current futility debate cannot be allowed to continue. In cases where it appears that treatment may be futile, the professional must be obligated to recommend an appropriate course of treatment, though that could mean recommending no treatment or only palliative care. However, it is imperative that the doctor discuss this issue openly with the patient and, if need be, with the patient’s family (especially in cases of incapacity or incompetence.) These discussions should not be avoided because there is a fear that the patient or family will

disagree with the professional's recommendation.

Patient authority needs professional authority, because it requires the physician to communicate effectively with the patient, recommend what he or she infers to be the best course of treatment, and an attempt to resolve any disagreement within the confines of the doctor-patient relationship. The ultimate imperative, however, is not to avoid these difficult and complicated discussions for fear of disagreement. The following chapter will illustrate a practical application of the models of patient and professional authority that I have been developing.

Chapter Five

Application of Patient and Professional Authority

There are many questions raised by the idea of medical futility, of which the following two are of particular relevance to the conceptions of patient and professional authority that have been developed in this thesis. The first question pertains to the issue of whether patients are entitled to insist on the implementation of medical treatment(s) that health care professionals believe to be futile.¹ The second question focusses on the issue of whether the patient's informed consent is required before futile treatment can be withdrawn or withheld?² This second question concerning a professional prerogative to withhold or withdraw these types of treatments unilaterally has developed as a response to the first question which pertains to some patients' desire to insist on "futile" treatments.

Respect for the principle of patient autonomy in cases like *Quinlan* reveals that patients and/or their families often refused treatment because they believed it was in some rudimentary sense "futile." The Quinlan family wanted to disconnect Ms. Quinlan's respirator because they thought she would not want to live life in PVS, presumably because the quality

¹State of Minnesota, District Court, Probate Court Division, County of Hennepin, Fourth Judicial District "In Re: The Conservatorship of Helga M. Wanglie." (1991).

²Super. Ct. Civ. Action No. 92-4820, Suffolk Co., Mass., verdict, (21 April 1995).

of her life was too low. This is both an autonomy decision and a “qualitative” futility judgment.³

The futility debate arose because of a shift in attitude, from a view where professionals believed that even a life like Karen Quinlan’s (PVS and respirator dependent) was appropriate to preserve by medical procedures, to a belief in the contrary. This shift is depicted through cases like *Wanglie*, where the medical facts are almost identical but the professional recommendation is the reverse. The fundamental underpinning of those who agree with the use of this term is the desire for unilateral decision-making authority by either the patient or the professional. As a result, these two questions can be synthesized into one, namely, who is properly entitled to decide when treatment is futile, the patient or the professional? Of course, the common sense usage of the word “futile” would imply that if treatment is futile then it should not be provided. However, one major concern arises with the actual futility determination itself.

A distinctive medical procedure of particular relevance to this discussion is cardiopulmonary resuscitation (CPR). CPR was developed as a rapid emergency procedure to rescue patients with acute life-threatening cardiac arrest.⁴ However, it has evolved to such an extent that patients have come to expect its implementation, in almost every cardiac arrest situation, unless otherwise stipulated.

³It is important to note that the Quinlan family believed that the respirator should be withdrawn because it was in a sense “futile.” However, they did not consider withdrawing artificial nutrition and hydration, presumably, because, they believed that feeding a person could never be futile.

⁴Schneiderman, L., and Jecker, N., *Wrong Medicine: Doctors, Patients, and Futile Treatment*, p. 45.

Existing guidelines promote CPR to restore life when cardiac arrest occurs from cardiac causes. Statutes which give an implied consent to emergency treatment are used to endorse CPR as the default response to cardiac arrest. It has become common policy to require CPR unless CPR is explicitly refused or futile.⁵

Since CPR is the default treatment for cardiac arrest, it is particularly relevant to the futility debate. CPR is a widely practised intervention that the lay public is very aware of. Thus, the patient's awareness and expectation of this intervention are not necessarily dependent upon the professionals' disclosure of its existence. Unlike other interventions, patients are usually aware that CPR is a possible alternative that generally requires consent to be denied. One of the common concerns of the futility debate is whether physicians should mention interventions that are believed to be futile. However, concerning CPR, patients do not require the physician to mention it because they have come to expect it unless otherwise stated.

The part of the above quotation that deals with the patient's explicit refusal is an autonomy issue and it is largely accepted that patients retain this negative right to refuse treatment.⁶ However, the part that deals with the futility of the procedure is very controversial, because as the debate is framed in the literature, there is no agreed upon definition of futility. As a result, a futility determination entails either a unilateral decision on the part of the professional or patient and could even result in a positive right on the part of

⁵Hilberman, M., et al., "Marginally Effective Medical Care: Ethical Analysis of Issues in Cardiopulmonary Resuscitation (CPR)," *Journal of Medical Ethics* Volume 23, (1997), pp. 361-367.

⁶Fish, A., and Singer, P., "Nancy B.: the Criminal Code and Decisions to Forgo Life-Sustaining Treatment," *Journal of the Canadian Medical Association*, Volume 145, Number 5 (1991), pp. 637-642.

the patient to demand treatment that the professional believes is futile. Therefore, it raises the familiar question of ‘who gets to decide if treatment (CPR) is futile, the doctor or the patient?’.

Application of Schneiderman and Jecker’s Proposal

In response to this question Schneiderman and Jecker argue, as we have seen in detail in Chapter Two, that CPR or any other procedure should be considered futile if it has not worked in the last 100 similar situations, or if the patient is not expected to live to be discharged from the intensive care unit or cannot appreciate the benefit of the procedure. If any of these conditions are met, then CPR or any other procedure is futile and should not be provided to the patient. In fact, Schneiderman and Jecker argue that the professional is ethically obligated not to provide treatment under these conditions, regardless of whether the patient requested it or not. In addition, these futility decisions should be made by the professional unilaterally.

To appreciate the appeal of this position, consider the following example. During his second lobectomy for cancer a 78-year-old man suffered a series of strokes that resulted in irreversible brain damage and he never regained consciousness.⁷ Several weeks after the surgery the patient developed abdominal bleeding which was corrected through surgery but recurred several months later. In addition to these facts, diagnostic tests indicated that renal

⁷Trau, J., “Futility, Autonomy, and Informed Consent,” *Health Progress*, (1994), pp. 40-72.

failure was immanent. The professional consensus was that the patient was headed for multi-system failure. The professionals then decided on two things: first they asked the family to agree to a Do-Not-Resuscitate Order and secondly, they unilaterally decided that if the man's kidneys failed they would not offer dialysis as a treatment option, because it would be futile.

According to Schneiderman and Jecker, it would be entirely appropriate for the professional to make these types of judgments unilaterally. In fact, other commentators argue that this type of decision-making exhibits the "best of paternalistic behaviour." Dr. Trau says:

Given the impact of illness on the emotional and psychological states of patients and their families and their resultant vulnerability, the omission of futile options from treatment plans is logical and exemplifies the best of paternalistic behavior.⁸

Dr. Trau goes on to say that if a treatment offers no benefit it would be irrational for the professional to offer it. She further suggests that the request for futile treatment could only be made by someone who does not understand the treatment's futility.⁹ This idea, that a patient who requests futile treatment does so out of ignorance, is a predominant theme of Stuart Youngner's. He provides an interesting example of a woman who was outraged at a house officer who asked if she wanted health care professionals to restart her 80-year-old husband's heart if it stopped. Youngner says:

Sometimes people make unreasonable demands because they simply do not understand "the facts." We assume too often that they do. When the 80-year-old patient's wife was outraged by the notion that a house officer might not want to "start up" her husband's heart if it stopped, she had little notion of what cardiopulmonary resuscitation involved or what the expected

⁸Trau, J., "Futility, Autonomy, and Informed Consent," *Health Progress*, (1994), pp. 40-72.

⁹*Ibid.*, pp. 40-72.

outcome was if her husband arrested.¹⁰

Commentators who agree with the use of the term “futility” and all that this term implies acknowledge that at a fundamental level most disagreements about these decisions result because the patient and/or family lack sufficient understanding and do not trust¹¹ professionals enough to appreciate what the professional is recommending. The tendency, as suggested by Schneiderman and Jecker and also Dr. Trau, is to advocate professional unilateral decision-making in these highly complicated situations, claiming that this demonstrates the best of paternalistic behaviour. However, it may be more important to eliminate the reasons for disagreement (ignorance and mistrust) as far as possible, rather than simply acting paternalistically.

Possible Responses to Unilateral Decision Making

In light of this paternalistic tendency, Edmond Howe, a professor of psychiatry, explains that there are three possible responses the patient and/or family may have to this type of professional unilateral decision-making:

(1) Many probably most, will feel grateful and supported, particularly if they want to refuse the intervention that their care provider considers futile. (2) Some will be compliant and decline the intervention, even though they genuinely prefer it, because they believe that they should defer to their care provider’s view. (3) Others, perhaps the smallest group, may feel offended

¹⁰Youngner, S., “Applying Futility: Saying No Is Not Enough,” *Journal of the American Geriatrics Society*, Volume 42, Number 8, (1994), pp. 887-889.

¹¹Caplan, A., “Odds and Ends: Trust and the Debate over Medical Futility,” *Annals of Internal Medicine*, Volume 125, Number 8, (1996), pp. 688-689.

because they believe that their physician is attempting to impose his or her view and, as if compulsively, these patients may oppose it.¹²

It is intuitively clear that number (1) is the most desirable outcome and number (3) is the least desirable, with number (2) being a little more ambiguous. In fact, number (3) is the patient response that has sparked the futility debate. In these types of situations, Caplan, Trau and Youngner would suggest that outcome (3) is based on ignorance or mistrust.¹³ If this is the case, then the most appropriate approach to these types of decisions should be one in which the probability of outcome (3) is reduced and the chances of outcome number (1) are increased. This could be accomplished by an approach which encourages methods that are designed to reduce levels of patient ignorance and mistrust; these methods would consist of, at least, a substantial amount of patient input (through conversation) and communication between the professional and the patient.

Outcome (3) is an exceptional case that does not occur frequently. However, its presence raises serious problems that can be prevented from developing if the situation is approached properly. Terrence Ackerman explains this in the following quotation:

Commentators who argue for unilateral decision-making assume that these cases of irresolvable conflict about the futility of treatment represent the paradigm clinical situations around which a policy should be constructed. [...] However, physicians and patients or surrogates almost always agree about the futility of a treatment if there has been careful and complete conversation

¹²Howe, E., "Discussing Futility," *The Journal of Clinical Ethics*, Volume 5, Number 2, (1994), pp. 91-99.

¹³Caplan, A., "Odds and Ends: Trust and the Debate over Medical Futility," *Annals of Internal Medicine*, Volume 125, Number 8, (1996), pp. 688-689.

about treatment goals that are both achievable and desirable.¹⁴

The important point here is that the professional and patient almost always agree about futility decisions if there has been careful and complete conversation; however, the essence of Schneiderman and Jecker's position is that this type of conversation need not occur. They argue that the professional could impose a futility label and limit treatment without any input from the patient and/or family at all. Therefore, since the likelihood of outcome (3) materializing increases as conversation and communication decrease, approaches that do not promote conversation and communication should be modified to focus on these central aspects.¹⁵

These types of decisions (futility decisions) require a subjective balancing of burdens and benefits, not an objective standard which can be appealed to without discussion. This subjective balancing must accommodate the types of concerns Younger, Trau and Caplan raise about "ignorance" and "mistrust." This can only be done with significant patient input and a significant amount of professional guidance, not by unilateral professional decision-making. The appropriate approach to making futility decisions, or any other clinical decision, must be able to prevent this type of disagreement from arising.

¹⁴Ackerman, T., "Futility Judgments and Therapeutic Conversation," *Journal of the American Geriatrics Society*, Volume 42, Number 8, (1994), pp. 902-903.

¹⁵Of course, one could always argue that the professional could communicate this information to the patient without necessarily requiring the patient's or family's consent. However, the probability of outcome number (3) will increase if the patient and/or family believe that their input is pointless. Admittedly, if professional unilateral decision-making is permitted the professional should be obligated to inform the patient and/or family that these types of decisions have been made. However, an approach which could minimize this outcome is definitely preferred to one that would increase it.

A Preventive Approach to "Medical Futility."

The overwhelming attention that the futility debate has generated along with its lack of a consensus, stems from its being the most recent manifestation of the age-old controversy between patient autonomy and professional paternalism.

[...] [O]ne basic source of the impasse regarding futility in the literature [...] it stems from a much older and broader impasse between the "patient autonomy" and "physician paternalism" camps in the bioethics debate.¹⁶

This latest expression of the "autonomy" vs "paternalism" debate, however, has reached an unprecedented deadlock. The literature in this field demonstrates a tremendous amount of inconsistency: for example, Gilgunn¹⁷ and the recent Manitoba court decisions¹⁸ have leaned away from patient autonomy, allowing physicians to override patient and/or family wishes concerning futility decisions. Whereas, landmark cases like Wanglie¹⁹ and the matter of Baby K²⁰ still exert considerable influence.

¹⁶Wear, S., and Logue, G., "The Problem of Medically Futile Treatment: Falling Back on a Preventive Ethics Approach" *The Journal of Clinical Ethics* Volume 6, Number 2, (1995), pp. 138-148.

¹⁷Super. Ct. Civ. Action No. 92-4820, Suffolk Co., Mass., *verdict*, 21 April (1995).

¹⁸Globe & Mail "Court gives MD last word on life." December 13, 1997. A 11-month-old baby was diagnosed as in PVS and courts granted physicians the power to refuse to resuscitate the baby despite parental objections.

¹⁹State of Minnesota. District Court et al. "In Re: The Conservatorship of Helga M. Wanglie." (1991).

²⁰United States District Court, E.D. Virginia, Alexandria Division "In the Matter of Baby K." (1993). The mother of an anencephalic infant [born without a brain] insisted that health care professionals provide emergency treatment to her child. The professionals refused, but nevertheless, the court ordered continued treatment despite the strenuous

Unfortunately, this type of dilemma is potentially devastating to the already fragile doctor-patient relationship. As Arthur Caplan suggests, the disagreement about medical futility threatens to undermine trust between the doctor and patient which is the relationship's very foundation. The desire for professional unilateral decision-making authority, without patient consent, demonstrates that professionals simply do not trust patients (and/or families) to participate in these decisions. This is explained in the following:

To put this in another fashion, at its heart, the push to legitimize the unilateral withholding [or withdrawal] of "futile" treatment by clinicians basically involves an indictment and complaint against patients and/or their families. Either or both are portrayed as unrealistic and unreasonable, as demanding that which they have – by definition – been told by professionals will not benefit and may well harm.²¹

I suggest that this debate has gone awry for two reasons: first, the actual term "medically futile" is very misleading; and secondly, the "medical futility" debate has overlooked the important lessons learned from the shared decision-making literature. If the term "futile" is abandoned and patients and professionals initiate an active shared decision-making process, which is maintained throughout the entire treatment process, these types of futility problems could, to a large extent, be prevented from arising.

The Futility of the Term "Futile"

objections of the attending physicians.

²¹Wear, S., and Logue, G., "The Problem of Medically Futile Treatment: Falling Back on a Preventive Ethics Approach," *The Journal of Clinical Ethics*, Volume 6, Number 2, (1995), pp. 138-148.

One of the main historical sources for the idea of futility is found in Greek mythology. The myth tells of two brothers who had large kingdoms, one brother had 50 daughters and the other had 50 sons. The children were set to marry but because of conflict between the two brothers it was called off. Eventually the wedding was rescheduled, but, as a result of bad feelings the daughters were ordered to kill their husbands on the wedding night. They did so. As a punishment they were condemned to hell to draw water eternally with leaky buckets (shaped like a sieve).

Initially it would appear that drawing water eternally with a sieve would be the height of futility but ironically, one might say that, in a sense, the leaky containers were not totally futile, because they served their punishing function. In this case, if the containers had been sealed, it would have totally destroyed the moral lessons the myth was meant to convey. Therefore, what appeared initially to be futile fulfilled a very useful goal.

Schneiderman and Jecker suggest that the term futility should serve as an ethical trump which relieves health care professionals from their duty to discuss these difficult issues with their patients:

Futility is a professional judgment that takes precedence over patient autonomy and permits physicians to withhold or withdraw care deemed to be inappropriate without subjecting such a decision to patient approval.²²

However, this mythological example helps to show that the word futile should not be used with such certainty. In one sense it is futile to eternally draw water with a sieve, if the goal is to transport the water somewhere; however, if the goal is something else like eternal

²²Schneiderman, L., Jecker, N., and Jonsen, A., "Medical futility: Its Meaning and Ethical Implications," *Annals of Internal Medicine*, Volume 112, (1990), pp. 949-954.

punishment as in the example, it is not futile at all. If this is applied to the *Wanglie* case, we see that treatment is futile in the sense that it cannot restore her to consciousness or to any previously enjoyed level of health. However, it was not futile if the goal was simply continued existence, even permanently vegetative existence.

For Helga Wanglie and her husband, human life — even unconscious life — was valued above and beyond considerations of its quality. In a context like this, calling treatments that preserve permanently unconscious life “qualitatively futile” sounds suspiciously like trying to redefine a debate about conflicting values into a debate about medical probabilities. And as doctors are generally the sole arbiters of medical probability this amounts to saying to families, “Your values don’t count.”²³

Since the futility of a procedure depends upon some conception of either the physician’s or the patient’s goals, which sometimes conflict. Therefore, perhaps it would be more appropriate not to use this ambiguous term “medically futile” at all. It appears that much of the medical futility debate is premised on the “proper,” “real” or “true” meaning of this word; it has an intuitive attraction because of its common sense usage, but ultimately this word implies more than it can support.

The philosopher C.L. Stevenson studied the way in which definitions influence individuals; he explained the importance of words, especially in ethics, and how individuals tend to impose ideas through persuasive definitions:²⁴

²³Weijer, C., and Elliott, C., “Pulling the Plug on Futility: Futility is not the Ethical Trump Card That Some Would Like it to Be,” *British Medical Journal* Volume 310, (1995), pp. 683-684.

²⁴“A ‘persuasive’ definition is one which gives a new conceptual meaning to a familiar word without substantially changing its emotive meaning, and which is used with the conscious or unconscious purpose of changing, by this means, the direction of people’s interests.” Stevenson, C., *Persuasive Definitions, in Facts and Values: Studies in Ethical Analysis*, (New Haven: Yale University Press 1963), p. 32.

The words are prizes which each man seeks to bestow on qualities of his own choice... Persuasive definitions are often recognizable from the words “real” or “true”... Since people usually accept what they consider true, “true” comes to have the persuasive force of “to be accepted”. This force is utilized in the metaphorical expression “true meaning”. The hearer is induced to accept the new meaning which the speaker introduces.²⁵

The term “futility” evokes this type of emotive response which is inappropriate within the confines of the clinical experience between doctors and patients.

There is a legitimate concern that simply abandoning a term is not part of a proper solution to any substantial problem. This type of objection is generally conceded, however, the impact of abandoning the term “futile” in this context is substantial. For instance, Schneiderman and Jecker, although they propose their own specific definitions of futility, argue that the more general principle that “at some point the probabilities of success are so remote that further treatment should not be attempted” and “at some point the patient’s quality of life is so poor that further treatment should not be attempted.” They argue that regardless of where the threshold is, once the label is applied the final decision most properly rests with the professional and should be made unilaterally. They argue that once the label is applied normal duties do not apply. Furthermore, the whole medical futility debate was generated, in large part, because of the uncertainty of a definition. It is because of these types of reasons that abandoning the term “futile” can bring a certain type of clarity to the debate. Regarding Schneiderman and Jecker’s position, if the label is inappropriate or should not be applied, then these decisions are not properly within the exclusive domain of the professional. In short, this term should not be made to serve as the ethical trump that some intend it to

²⁵Stevenson, C., *Persuasive Definitions, in Facts and Values: Studies in Ethical Analysis*, (New Haven: Yale University Press, 1963), p. 212.

serve as.

Shared Decision-Making

My second contention, more closely related to the ideas of patient and professional authority, concerns the idea of shared decision-making as a preventive approach to avoiding instead of resolving conflict within the doctor-patient relationship. Most discussions of medical futility have missed important aspects of the situation. The examples that have framed this debate begin at a time after positions are already established. Health care professionals have already determined that treatment is futile and that patients (and/or their families) request it nevertheless. Stuart Youngner addresses this often overlooked issue:

However, these cases are but snapshots in time and give little perspective of the historical, social, and personal context in which these situations arise and that motivate people to demand interventions when competent and compassionate health professionals would say no. Taking better account of these motivations will not tell us where to draw the line. Nor does understanding motivation mean caving in to unreasonable demands. Such understanding does, however, offer the opportunity to provide optimum care for dying patients and their families and to promote shared decision making.²⁶

To explain what Youngner means by shared decision-making it is necessary to look

²⁶Youngner, S., "Applying Futility: Saying No Is Not Enough," *Journal of the American Geriatrics Society*, Volume 42, Number 8, (1994), pp. 887-889.

at the President's Commission²⁷ and Jay Katz²⁸ who have argued for a shared decision-making model of the doctor-patient relationship. Their arguments developed through the informed consent literature where they argue that the doctrine of informed consent did not fulfill its full potential of respecting patient autonomy, in any meaningful way, and as a result the doctor-patient relationship was left lacking.²⁹ To support their reasoning, Katz and the Commission argue the following:

As a result they [the courts, doctors and patients] have missed the opportunity to move toward what is needed: a new and unaccustomed dialogue between physicians and their patients [...] in which both, appreciative of their respective inequalities, make a genuine effort to voice and clarify their uncertainties and then to arrive at a mutually satisfactory course of action.³⁰

The extreme positions concerning the futility debate reveal that this deficiency is still present in the doctor-patient relationship. Instead of embarking on a new approach toward this relationship, commentators have simply tried to stake out a piece of terrain as belonging to either the doctor or patient.³¹ This is illustrated in the following analogy by Howard Brody:

²⁷*President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*, p. 30.

²⁸Katz, J., "Informed Consent – A Fairy Tale? Law's Vision," *University of Pittsburgh Law Review*, Volume 39, Number 2, (1977), p. 318.

²⁹ *Ibid.*, p. 318.

³⁰*President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*, p. 30.

³¹Brody, H., "The Physician's Role in Determining Futility," *Journal of the American Geriatrics Society*, Volume 42, Number 8, (1994), pp. 875-878.

Suppose that a new island has just been discovered, and explorers from various nations are eagerly planting their flags and laying claim to various pieces of territory. I am trying to plant the flag of professional integrity somewhere on this island. I am not claiming that, compared with the territory claimed by autonomy, the territory in which professional integrity rules will be very large at all; indeed it may turn out to be very small and hardly worth fighting over. It is simply my goal to establish that somewhere there is a set of treatment decisions over which professional integrity will hold sway, even against contrary claims of patient autonomy.³²

Attempts to divide decision-making authority within this relationship simply frame the issue as a type of power-struggle in which the result is a zero-sum-game. However, the model of shared decision-making approaches this situation with the goal of making good decisions and does not get preoccupied with the secondary question of ‘who decides when there is a disagreement?’.

The problems that have developed as a result of the medical futility debate indicate that this type of shared decision-making process is a plausible way of preventing futility issues from arising. However, shared decision-making, as developed in the informed consent literature, is not a step by step method that can be rigidly adhered to. Rather it is an active process through which the doctor and patient participate with the shared goal of making the most appropriate (i.e., good) decisions. Nevertheless, the President’s Commission does state some necessary conditions required for a genuine shared decision-making process:

Without seeking to provide the last word on this much-discussed subject, the Commission believes the core elements fall under three headings: (1) the patient’s current medical status, including its likely course if no treatment is pursued; (2) the intervention(s) that might improve the prognosis, including a description of the procedure(s) involved, a characterization of the likelihood and effect of associated risks and benefits, and the likely course(s) with and without therapy; and (3) a professional opinion, usually, as to the best

³²Brody, H., “The Physician’s Role in Determining Futility,” pp. 875-878.

alternative. Furthermore, each of these elements must be discussed in light of associated uncertainties.³³

A common theme of the Commission's core elements of shared decision-making is the requirement of the physician to communicate with the patient and/or the family, in a very effective way. The extent of this communication is very broad. The physician is required to communicate the patient's current medical status, any relevant interventions that might improve the prognosis, a discussion of possible risks and benefits, the likely course with and without therapy, a professional recommendation as to the best alternative, and finally, a discussion of the associated uncertainties.

Weijer and Elliot explain that this strategy should be extended to the medical futility debate:

When patients or families demand treatment that is unlikely to produce a good outcome doctors ought to disclose carefully the treatment options [including no treatment], the likely outcomes, and the probabilities of attaining those outcomes.³⁴

Within the context of the medical futility debate, an ongoing communication process involving these various components could help to prevent the complex disagreement between the doctor and patient (and/or family) that characterizes this debate. This type of approach has been attempted by Donald Murphy, who is the director of a nursing home, and demonstrates promising potential:

³³*President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*, p. 74.

³⁴Weijer, C., and Elliot, C., "Pulling the Plug of Futility: Futility is not the ethical trump card that some would like it to be," *British Medical Journal*, Volume 310, (March 1995), pp. 683-684.

Donald Murphy reported that when he became medical director of a nursing home, only 10% of the multiply impaired, elderly patients had do-not-resuscitate orders. He changed the way the issue was approached. He encouraged discussions about death and dying and avoided using misleading euphemisms like, "Would you want us to do everything possible to save your life if your heart stopped beating?" When he provided patients and families with accurate descriptions of their medical conditions, poor prognoses, and the unpleasant realities of dying in critical care environments, they uniformly (23 of 24 patients and all but one relative of incompetent patients) rejected resuscitation. None refused to discuss these difficult issues because they felt uncomfortable. By taking this direct approach, Murphy truly empowered his patients and their families and avoided the "gun fight at the OK Corral," where futile CPR is demanded and physicians must "draw" their futility trump card.³⁵

This type of shared decision-making process between the doctor and the patient is the essence of the model of patient and professional authority and the doctor-patient relationship that was articulated in the previous chapters.

The Ideal of Shared Decision-Making

The ideal of shared decision-making recommended by the President's Commission needs to be stated carefully. It is liable to misinterpretation in the following way.³⁶ Shared decision-making can be seen as a two-fold division of labor: the Physician's task is to provide facts, treatment alternatives, prognoses, risks and uncertainties. The patient provides the values and selects from the options provided by the physician in terms of these values.

³⁵Youngner, S., "Applying Futility: Saying No Is Not Enough," *Journal of the American Geriatrics Society*, Volume 42, Number 8, (1994), pp. 887-889.

³⁶Brock, D., "The Ideal of Shared Decision-Making Between Physicians and Patients," *Kennedy Institute of Ethics Journal*, (1991), pp. 24-47.

Dan Brock utilizes this simplified statement of the ideal of shared decision-making to argue that such a model seriously misplaces the role of patient's values. The simple model requires that the physician take the patient's values as incorrigible, as something concerning which the patient can not be mistaken. This is a deeply subjective view of values. The point Brock makes is that patient's values can be questioned, discussed and explored and not simply taken as trumps that bring any decision-making process to an abrupt end.

Brock maintains that the preferred theory of the good life for a person contains objective components. These components include health, in a physical, mental and social sense.³⁷ I take this to mean that an illness of the body is not reasonably included in any one's conception of the good life, nor is the loss of one's mental capacities or the ability to communicate. Given this background, Brock remarks:

The more the patient's values and choices in shared decision-making appear to be in conflict with his or her objective good ... the stronger the case for the physician being an advocate for those ideals and functions and seeking to insure that the patient's values and choices do not, in fact, conflict with them.

The rationale for a physician's probing more deeply into a patient's values, then, and rejecting the simple division of labor described above, is based on this conception of what is objectively good.

Brock is under no illusion that this conception of the objectively good will solve all the problems in this area. He describes it as a continuum, where at one end we have the notion of what is objectively good and at the other extreme we have a conception of values in a deeply subjective sense. The subjective end of this continuum of values would dictate

³⁷*Ibid*, pp. 22-47.

that we accept the choice of a Jehovah's Witness to refuse blood products even in the face of death. Brocks point is that we would not question in any deep fashion the person's religious beliefs but we might ensure they understand the difference between blood products and some of the other products that are available that Jehovah's Witnesses will accept.

Professional and Patient Authority

The goal of professional authority is to acquire voluntary deference to the professional's judgment by the patient because of the patient's assumption that the physician has superior competence in these matters. In order to achieve this, the professional must elevate the patient to a heightened level of decision-making, where the physician and patient are mutually involved in the decision-making process each step of the way. It is not possible for the patient to exert legitimate authority without the professional fulfilling the crucial role of an informer and to an extent educator. In this regard, patient authority, rests upon, or is supported by, professional authority.

The previously developed models of patient and professional authority could help prevent these diametrically opposed futility disagreements from materializing. This model of patient and professional authority involves abandoning the word "futility" and articulating exactly what the problem with the requested procedure is. Therefore, if the professional believes that the patient's quality of life is so compromised that CPR would not be beneficial regardless of whether it could be successfully implemented, or, if the professional believed that the chances of CPR being successful are too remote to be worth trying, he or she must

be obligated to discuss this with the patient, not simply employ the ethical trump and label further treatment futile. Further, this discussion must take place prior to the time when the professional deems it appropriate to withhold or withdraw treatment. There should be no surprises to anyone.

The professional and patient authority models that I have developed would enable substantial patient input throughout the entire decision-making process, instead of only at the “one time” of making the futility decision. If the patient is involved in each step of the process, he or she will be able to access information with the professional guiding him or her, as it develops. If this is done over the course of treatment, by the time the professional recommends that CPR not be provided or some other form of treatment be discontinued, he or she and the patient (and/or family) should be on the same “wavelength.”³⁸

Recall the case of the 78-year-old man who was going through his second lobectomy for cancer, unconscious and headed for multi-system organ failure where the attending physicians believed that a do-not-resuscitate order was appropriate and maintained that if his kidneys failed they would not offer dialysis because it would be futile. This model of professional and patient authority would require that the professionals behave in almost the same way and make the same recommendations. However, if this were all that is required the possible outcomes would be one of the three that were outlined above: (1) the patient and/or his family would agree with the physician and comply, (2) the patient and/or family would disagree but still comply or (3) the patient and/or family would disagree and resist. The benefit of this new model of patient and professional authority requires the additional element

³⁶Youngner, S., “Applying Futility: Saying No Is Not Enough,” pp. 887-889.

of substantial patient (and/or family) input. This would reduce the chances of outcome number (3) where the patient refuses to comply with recommended plans.

This type of professional authority and patient authority model will improve communication between professionals and patients. Patients that are knowledgeable about their condition usually recover from therapy in better health, and they do so faster. Of course, in futility cases the issue is not about helping the patient recover faster, because recovery is not expected. However, studies indicate that knowledgeable patients (and by extension their families) tend to comply more easily, that they have reduced levels of anxiety, and that their participation in the decision-making process reduces levels of ignorance and mistrust.³⁹ Further, patients who are informed and are active in the decision-making process can further their own life plans; unfortunately, in futility cases this would most likely consist of the patient (and/or family) arranging for the patient's imminent death.

The imperative of the futility debate should be to prevent these opposing positions from developing. Gillon explains how important it is to prevent these situations from arising by refraining from using pejorative terms like "futile" to justify the professional's unilateral withholding or withdrawal of treatment:

[...] it is this tendency to produce hostility in cases of disagreement that is perhaps the strongest reason for avoiding use of the term "futile" and its cognates in the context of withholding or withdrawing potentially life-prolonging medical interventions. As noted above the term carries with it a strongly negative connotation – "uselessness" in the face of life-threatening disease is not generally appreciated, especially in doctors, and the natural anger of a dying person and his or her relatives is often directed not only at

³⁷*President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*, p. 70.

the interventions that fail to preserve life but also at the medical and nursing staff who carry them out.⁴⁰

This natural anger that Gillon is referring to arises as a result of patient ignorance and/or mistrust of the professional. Of course, a natural human tendency in these highly emotional end-of-life situations is to react in anger, but the professional's employing these belittling terms does not help the situation, nor does it help to alleviate ignorance or mistrust.

It is absolutely crucial to approach the doctor-patient relationship with the agenda of minimizing patient ignorance and mistrust. My suggestion is that the most plausible way of doing this is to implement the previously developed model of patient and professional authority which will result in a form of active shared decision-making. This is the most appropriate way to minimize these corrosive qualities (ignorance and mistrust) and promote trust by sufficiently informing the patient and allowing a significant amount of patient input and participation in the decision-making process.

³⁸Gillon, R., "Futility-Too Ambiguous and Pejorative a Term?" *Journal of Medical Ethics*, Volume 23, (1997), pp. 339-340.

Conclusion

The doctrine of informed consent affirmed, through the landmark Canadian ruling in *Reibl v Hughes*, holds that patients are entitled to sufficient information to make an informed decision. It was decided that the physician had a duty to disclose to the particular patient the amount of information that a reasonable person in the patient's position would want. Further, if it was proven that the physician failed to fulfill this duty to disclose, he or she would be guilty of negligence. In practical terms, the patient's role in the doctor-patient relationship was limited to the ability to consent or not consent to treatment. This is commonly referred to as the patient's negative right to refuse treatment.

This negative right developed because society and the courts realized that the appropriate course of medical treatment often rested upon a subjective judgment about the patient and about what constituted his or her best interest. The physician's obligation to disclose sufficient information to the patient for informed consent developed because it was acknowledged that although the patient knew best what constituted his or her best interest, a significant amount of medical information was still required in order for the patient to make an informed decision and thus achieve his or her best interest. Therefore, "informed consent" consisted of two distinct elements: "inform" which constituted the duty of the physician and "consent" which was within the proper realm of the patient's authority.

The doctrine of informed consent established very clear roles for the doctor and patient in this relationship. The professional's primary duty was to inform the patient of the technical medical information and the patient's role was to either consent or refuse. The cases of Karen Quinlan and Nancy B are good examples of patients (and/or their families) exercising this type of negative right to refuse treatment. However, around 1989-1990 a new phenomenon developed called the idea of medical futility. This new idea threatened the robust position that the principle of respect for patient autonomy occupied.

The idea of medical futility raised many important questions, such as: if treatment is determined to be futile (by the professionals) then is the patient (and/or family) entitled to demand it? Or, if treatment is determined to be futile, does the professional have an obligation to elicit the patient's informed consent before withholding or withdrawing treatment? Basically, the idea of medical futility raised the nagging question of who should decide if treatment is futile, the doctor or the patient?

One of the first revelations of this new debate was that futility was not a technical medical matter that required technical medical expertise to determine, as with a diagnosis. A diagnosis requires the physician to exercise a certain amount of esoteric knowledge which is germane to medical practice, whereas, a futility decision, such as a decision of whether to resuscitate a person, does not require the exercise of the same type of knowledge. The decision of whether to resuscitate a person rests upon different considerations, such as the quality of the patient's life both before and after treatment, or the probabilities of the invasive resuscitation effort being effective. Thus, it was acknowledged that futility decisions required a certain level of value judgments.

Lawrence Schneiderman and Nancy Jecker suggested two different conceptions of futility:

first a quantitative sense of futility and then a qualitative sense. The quantitative sense admitted that there was a significant amount of uncertainty pertaining to medical practice, but they presumed that if a treatment has not worked in the last 100 attempts it should be considered futile. Likewise, for qualitative futility, if the patient could not appreciate the benefit of current or future treatment or if he or she will not live to be discharged from intensive care, treatment should be considered futile.

Schneiderman and Jecker offer specific thresholds for a futility determination and they provide very detailed and elaborate arguments for their standards. They concede that a lot of people may disagree with their specific standards but argue that most people would accept the more general claims that (1) at some point the probabilities of treatment being successful are so remote that it should be considered futile and that (2) at some point the quality of the patient's life is so poor that treatment should also be considered futile. However, their fundamental position is that if treatment is "futile" then it is properly a medical judgment and that the physician should be ethically obligated to either withhold or withdraw futile treatment, without patient consent.

The debate over "who decides?" if treatment is futile has raged throughout most of the present decade. Well-known commentators in the Bioethics literature advocated for unilateral decision-making power for one side or the other either doctor or patient, and have generated a wealth of literature. However, my contention is that the advocacy for unilateral decision-making power has obscured the legitimate roles of both the professional and the patient in this unique clinical relationship. The futility debate has been framed as a power struggle in which the outcome is a zero-sum game. In other words, if one side wins the other side loses. Therefore, I have approached the issue from a new angle, the angle of authority; and I have attempted to articulate exactly what the legitimate domains of patient and professional authority are within the doctor-patient relationship.

On my model, physician authority and patient authority are mutually reinforcing, rather than competing. While my model grants more authority to physicians than the 'independent choice' model, this enhancing of physician authority does not diminish the authority of the patient (as the zero-sum model assumes). On the contrary, enhancing physician authority actually helps to enhance the patient's authority because it elevates the patient to a level where he or she is competent, and has the requisite knowledge and guidance, to make a good decision. Similarly, while my model grants more authority to patients than the Schneiderman and Jecker model, this enhancing of patient authority does not diminish the authority of the physician. On the contrary, enhancing patient authority actually helps enhance the physician's authority because it provides the physician with a unique insight into the patient's perspective which can help create trust and eliminate patient ignorance. Thus, enabling the physician to prevent misunderstandings and conflict when agreement in decision-making is crucial.

The model of patient authority that I developed consisted of three components: (1) the patient's esoteric subjective knowledge concerning his or her own best interest, (2) respect for the principle of patient autonomy, and (3) a negative right to refuse unwanted medical treatment. Along the same lines, the model of professional authority is also threefold: (1) the physician must have the required technical knowledge and be technically competent, (2) be committed to the principle of beneficence, and (3) possess the required interpersonal skills. The interpersonal skills ingredient consists of an additional three elements: (1) effective communication skills, (2) a professional recommendation, and (3) an acceptance of disagreement and a serious attempt to reconcile that disagreement within the confines of the same doctor-patient relationship.

The intention of articulating these detailed models was to develop a preventive approach to

the issues pertaining to medical futility. Instead of framing the issue as a power struggle, where it was necessary to assign decision-making authority to either the professional or the patient, I developed a model of patient and professional authority which would reveal itself as a type of active shared decision-making. This shared decision-making process takes a preventive approach to futility and attempts to preclude these irreconcilable futility situations from developing.

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